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Galvani, SA, Dance, Cherilyn and Wright, Samantha (2018) Experiences of hospice and substance use professionals: End of Life Care for People with Alcohol and Drug Problems. UNSPECIFIED. Manchester Metropolitan University.

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October 2018



RESEARCH REPORT

Experiences of hospice and substance use professionals: End of Life Care for People with Alcohol and Drug Problems

“People present with complex and multiple needs including mental ill health and social care needs. The stigma and ‘demonising’ attitudes they face, negatively affect their engagement with health and social care.”

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Executive Summary

1. This report presents the findings of one strand of a research study entitled 'End of Life Care for People with Drug or Alcohol Problems'. It focusses on people working in hospices or in substance use services as paid staff or volunteers, and their experiences of supporting people who have both substance use and end of life care needs.
2. The aims were to i) access the views and experiences of a range of health and social care professionals in delivering end of life or substance use care to individuals and their family members, friends and carers (hereafter, families) where people experienced both issues; ii) assess professionals' attitudes towards supporting people with problematic substance use and chronic or terminal illness; iii) establish the challenges and opportunities professionals face in supporting people with problematic substance use and chronic or terminal illness
3. Data were collected using a mixed methods approach including a self-completion survey, focus groups and individual interviews with professionals working in substance use agencies and in hospice services.
4. Just over half the hospice professionals thought they would be aware of a person's problematic substance use and nearly all the substance use professionals anticipated serious ill health as related to the person's problematic substance use.
5. Substance use professionals did not find it easy to identify end of life and hospice professionals did not find it easy to identify problematic substance use. Hospice staff faced challenges of determining which signs and symptoms related to the health condition or the substance use. Similarly, substance use professionals commented on fluctuating substance use alongside a fluctuating health status making identification of people in need of end of life care more difficult.
6. Hospice staff had worked with more people with problematic substance use and end of life care needs than substance use colleagues although this was still a small proportion of their work. That said, both groups were aware there was an unmet need and had seen numbers of people presenting with both issues increasing.
7. Practice challenges fell into three core groups: challenges for people with experience of services, challenges for individual professionals and their practice, and challenges for organisations and at a system level.
8. A clear thread through all the data sources was the reported complexity and multiplicity of needs that this group of people often present with including mental ill health and social care needs.
9. Professionals reported stigmatising attitudes from society and other professionals towards this group of people. This, in turn, negatively affected their health and social care, particularly from acute and primary care.
10. The current climate of 'recovery' focussed substance use services presented challenges for professionals working with this group of people who will not recover but who deserve as good a death as possible.
11. Difficulties asking or talking about the 'other' issue was a clear theme across both substance use and hospice groups. In particular, when to ask, how and what to ask, and concern about the implications of asking.
12. There was no routine assessment of these potentially overlapping needs with a lack of confidence, willingness, concern about appropriateness, and worries about opening 'Pandora's Box' being among the reasons for professionals not doing so.

13. Substance use, and problematic substance use in particular, was seen to divert appropriate health responses from primary and acute services.
14. There was a lack of clear pathways for this group of people to access the services they needed and difficulties in effecting a positive multi-agency response.
15. Symptom and pain management was a major challenge for hospice professionals in particular. Concerns included over- and under-prescribing of pain medication, the misuse of pain medication by the individual or their family and friends, and people using a range of substances, including cannabis oil, herbs and spices, to medicate their pain without medical staff knowledge.
16. Families and friends of people receiving end of life and substance use services also presented a challenge to professionals. The key areas were problematic substance use by family members, the challenges of working with or contacting estranged family members, and managing family responses to their relative's continued substance use at the end of their lives, including anger and frustration.
17. Professionals working in both services identified frustration, sadness, emotional stress and concerns about personal safety when supporting people with problematic substance use at the end of their lives. However, they identified positive team support from colleagues as helping them to cope with the strain.
18. At a systems level, the current funding cuts and austerity measures led to pressures on professionals due to gaps in services, slow response rates from other professionals, or their inability to provide the service in the way they felt it should be delivered.
19. While some partnership working was evident, there was substantial variation from agency to agency and a clear lack of agreed care pathways for this group of people. Substance use agencies, in particular, felt marginalised in the multi-disciplinary meetings yet felt they were often the only ones working with people in a holistic way .
20. There was a range of training needs identified by professionals to improve their knowledge and confidence, including how to talk to people about their end of life care or substance use needs.
21. There were a number of examples of good individual and agency practice both in terms of practical support for this group of people as well as positive and empathetic attitudes towards them. This good practice needs disseminating widely.

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PART ONE:
BACKGROUND AND RESEARCH METHODOLOGY

Chapter 1. Introduction

This report presents the findings of one strand of a research study entitled ‘End of Life Care for People with Drug or Alcohol Problems’. It focusses on people working or volunteering in hospices or in alcohol and drug (hereafter, substance use) services and their experiences of supporting people who have both substance use and end of life care needs.

A number of factors, such as increasing longevity of the UK population, increasing alcohol-related harm among older drinkers, an ageing cohort of long term drug users, along with growing awareness of palliative care services and support at the end of life, indicate that numbers of people with these overlapping issues might be expected to grow.

However, at the inception of this study, little was known about the extent to which either hospice or substance use services might encounter individuals with both substance use problems and end of life needs. In addition, hospice services in the UK have tended to be focused on working with individuals with a cancer diagnoses rather than the broad range of people living with a range of terminal conditions (see Care Quality Commission, 2016). This was also identified in other strands of this research, in particular, the Rapid Evidence Assessment (Witham et al., 2018) and the key informant interviews (Templeton et al., 2018). Thus, there were questions about whether professionals working in hospice settings recognised, and responded to, substance use by people or their relatives.

In relation to substance use services, recent policy and practice attention has been focused on a framework of ‘recovery’ and on helping people to ‘recover’ from their substance use problems (Care Quality Commission, undated). This recovery focus begs questions about how those working in this field then recognise and respond to people who have serious health problems and, possibly, end of life care needs.

‘Substance use’, and ‘death and dying’, can each raise uncomfortable feelings for people with limited experience of them. Discussions about ‘end of life’ or ‘palliative care’ can force self-reflection on, and acknowledgement of, our own mortality and vulnerability to illness (Ingebrechtsen and Sagbakken, 2016). At the same time, societal attitudes towards substance use, particularly illicit substances, tend to be negative, and those who experience problems are a stigmatised and stereotyped group (Livingston et al, 2012). When linked with terminal illness, people with problematic substance use can easily be considered less ‘deserving’ of care, especially when illnesses may be associated with what is seen to be ‘lifestyle’ or ‘behaviour choices’.

In line with other strands of this research programme the study was exploratory in nature, seeking to understand the extent to which these over-lapping needs presented in the two types of service setting – hospices and substance use services. Further, it sought to explore how professionals responded and what sort of challenges arose. The exploration of existing research evidence (Witham et al., 2018) revealed a dearth of literature on this topic and only a handful of studies that reflected the experiences of professionals supporting people with end of life care or substance use needs.

Chapter 2. Methodology

This section sets out the aims of the study and provides an overview of the approach to sampling and recruitment the different forms of data collected and the ways in which data were analysed.

2.1 Aims

The overall aims were to:

1. Access the views and experiences of a range of health and social care professionals in delivering end of life or substance use care to individuals and their family members, friends and carers (hereafter, families) where people experienced both issues.
2. Assess professionals' attitudes towards supporting people with problematic substance use and chronic or terminal illness.
3. Establish the challenges and opportunities professionals face in supporting people with problematic substance use and chronic or terminal illness?

2.2 Research design and sampling

Given how little was known about the experience of professionals working with people who have both end of life and substance use needs, this strand of the study used a mixed methods approach which included a survey, focus groups and individual interviews with professionals working in substance use agencies and in hospice services.

Following satisfactory ethics review, the three data collection methods ran sequentially, with the survey largely providing information about range and frequency of experience while the narrative data from focus groups and interviews yielded much richer descriptive data which permitted deeper exploration of issues as experienced by participants.

The participants for each of the three data collection methods were drawn from those working or volunteering in the three hospices and two substance use agencies who were practice partners for this study: these agencies also participated in other strands of the study. All the hospices and one of the substance use agencies were based in the North West of England and the other substance use agency was based in the Midlands area of England. All of the organisations were based in areas of high deprivation according to the indices produced by the Department for Communities and Local Government (DCLG, 2015). Rates of substance use were also higher than average in these locations.

Invitations to participate in the survey were distributed by key contacts in each of the five participating agencies along with information about the study. The survey was open to all staff, paid and unpaid, whose work brought them into contact with people with experience or their families. In four sites, participants used the online survey; returns from one hospice were on paper. Participation was voluntary and the survey ran for six weeks in each of the five sites between mid-July to mid-September 2017.

In total, 72 survey responses were received from hospice professionals and 41 from those working in substance use services. Reliable estimates of the numbers of potential survey respondents were not possible due to a lack of data from the participating agencies. This means that response rates could not be assessed. It was, nevertheless, very clear that the number of responses varied substantially across the agencies. Responses from the hospice

professionals ranged from 9-48 per organisation; fewer substance use professionals responded (19 – 22 per organisation).

Key contacts in each of the sites also facilitated the arrangements for staff to be able to attend focus groups. One focus group was conducted in July 2017 and the remainder in September the same year. As is usual in focus groups, research participants self-selected to join a group. A total of seven focus groups were undertaken, one at each hospice site and 4 in substance use services. Overall, 43 people took part in one of seven focus groups with individual groups ranging from five to eight participants. While the majority of participants in substance focus groups were recovery practitioners and the majority attending hospice-based focus groups were nurses, other disciplines were represented in both groups including social workers, a spiritual care coordinator, and complex case workers, for example. Further demographic details are presented in table 2.1 (see section 2.6).

A further 10 individual interviews were undertaken. These individual interviews were undertaken for three main reasons: first, to record the perspectives of managers (none of whom had been invited to participate in the focus groups in case their presence constrained the discussion among staff and volunteers); second, to capture the experiences of staff/volunteers who had been unable to attend the focus group dates; third, to purposively sample staff from a range of professional disciplines (i.e.: nurses, recovery practitioners, social workers, doctors, counsellors and other social care professionals).

2.3 Research tools

Throughout this strand, the focus was on the experience of professionals within either the hospice or the substance use sectors, in relation to working with ‘the other problem’. By this we mean, how hospice staff experience and work with people who have current or past substance problems; and how substance use professionals work with and respond to people with end of life or palliative care needs. Thus, in the case of the survey and the focus group tools, two versions were created; one focusing on the substance use issues from the perspectives of those delivering end of life or palliative care services and the other exploring experience with end of life issues among those delivering substance use services. Only one tool was needed for the individual interview.

All of the tools used in this strand of the study were developed with the support of the project’s advisory group and the project’s group of community and practice partners. Tool development also drew on the (then emerging) findings of the project’s rapid evidence assessment and key informant interviews (Witham et al., 2018; Templeton et al., 2018).

2.3.1 Self-completion survey

Two survey tools were developed which mirrored each other: one addressing hospice professionals’ experiences of working with people who have a history of problematic substance use and the other examining the experiences of substance use professionals in working with people who are nearing end of life.

Each survey had five sections and 45 questions, including an embedded knowledge and attitudes scale (adapted from Cartwright’s AAPQ, 1979; and Venkat et al, 2017. See below for further detail). A training needs scale adapted from Galvani et al., (2013) was also

included. The survey questionnaire was available to complete on paper or online, with the latter delivered using the Qualtrics platform (Qualtrics, Provo, UT). The five sections explored participants’:

1. Role within the service and time in the organisation and service sector
2. Experience of working with ‘the other problem’
3. Experiences of working with ‘the other service’
4. Knowledge and confidence in working with ‘the other problem’ and perceived training needs
5. Demographic information

2.3.2. Adapting the AAPPQ and SAP and piloting the survey tool

Embedded within the survey was a tool to measure professionals’ knowledge about and attitudes towards working with the ‘other’ problem. An adaptation of the Alcohol and Alcohol Problems Perception Questionnaire was used for this purpose. This tool was originally created to assess the attitudes of helping professionals (who were not substance use specialists) towards working with people with alcohol problems. It is a scale that has been adapted many times and has for example been used to address alcohol and drugs, rather than alcohol only. Shorter versions of the original 30 item AAPPQ are available and in this study we used the 10 item version developed by Anderson and Clement (SAAPPQ: 1987). We also added five questions from the Survey of Attitudes and Perceptions (SAP: Venkat et al. 2017), since these seemed relevant to the focus of this study. To our knowledge these questionnaires have not previously been used to assess professionals’ knowledge and attitudes in a completely different practice area. Changing the questions from a focus on ‘alcohol or drugs’ to focus on ‘end of life’ or ‘palliative care’ needs resulted in a coherent questionnaire to explore substance use workers perceptions of their knowledge and confidence in working with end of life issues. Adapting the SAAPPQ and the SAP in this way was also advantageous in that direct comparisons were possible between the two groups of professionals.

2.3.3 Focus groups and interviews

Focus group discussion guides were designed to explore some of the issues identified in the survey in greater depth. Individual interviews additionally sought to pick up on some of the findings from other strands of the study, particularly the evidence assessment (Witham et al 2018 and the key informant findings (Templeton et al, 2018).

Two focus group tools were developed to reflect the different working contexts for those in substance use services and those in hospices. Briefly, the focus group tools aimed to encourage discussion of:

- The extent to which ‘the other issue’ was encountered by participants,
- Any challenges that the overlapping issues might present and how this was perceived to be managed within their organisations.
- What sort of role participants perceived there might be for ‘the other service’ (e.g. referring to substance use services from palliative care)
- What sort of training participants felt might be helpful to them for working with ‘the other issue’.

The interview schedule focused more on the organisational response to ‘the other issue’ and perceptions of how staff managed working with people who had both problems, particularly how they were supported to deal with some of the challenges they encountered. The interview also addressed joint working, training and service development, and questions about the current policy landscape and any impact there might be on practice.

2.4 Data analysis

As mentioned, the survey contained both open and closed questions. The closed questions were largely measures of frequency or extent of different types of experience and descriptive statistics are used to present the findings.

Scores were calculated for each participant on the domains of the knowledge and attitudes scale (see chapter 3) and the importance of training scale. Scale reliability co-efficients were calculated for the knowledge and attitudes scales and some comparative analyses were undertaken when appropriate, although these should be considered descriptive rather than inferential given the relatively small numbers and the fact that response bias cannot be assessed.

Analysis for both forms of qualitative data collection used Template Analysis (King, 1998). Template analysis is a type of thematic analysis that includes a two-stage approach to analysis. First, it involves setting *a priori* codes based on the questions included in the research tool and initial reading of a sample of the data – this forms the initial template; second, it involves more grounded or ‘bottom up’ coding to ensure that the data are closely and rigorously considered. This acts as both a quality control check on the *a priori* (and by nature subjective) codes developed for the template initially, as well as enabling new themes to be developed from a closer analytic relationship with the data. The advantage of template analysis over some other forms of thematic analysis is that it acknowledges, through the *a priori* codes, the intent of the researchers to focus on particular areas of interest. It is, therefore, more honest and transparent in relation to where the codes or themes stem from rather than arguing that they were all ‘emergent’ from analysis of the data. However, the grounded coding stage also ensures that new themes are identified and data are not missed.

Three authors were all involved in the data analysis and at least two researchers undertook some coding of the two qualitative data sets (focus groups and interviews) as a quality control measure.

2.5 Ethics

The study complied with the principles of voluntary participation, right to withdraw and safeguarding of confidentiality and anonymity of those taking part. All data were stored securely on encrypted drives or memory sticks. Audio recordings were deleted following validation of transcriptions. Tools, processes and recruitment arrangements were scrutinised and approved by the ethics committee of Manchester Metropolitan University.

2.6 Sample characteristics

Demographic characteristics of those participating in the three data collection activities are presented in table 2.1 (data unavailable for three focus group participants). The majority of respondents in both sectors were female, aged between 45-54 years and White British. It is notable that only the hospice had respondents over the age of 64 years. For both sectors, the majority of religious affiliation was Christian. Most respondents were paid employees, with a similar percentage of volunteers responding in both samples. Most respondents were in practitioner roles, including support workers. There was a vast range in terms of length of practice in their specialist field, ranging from one month to 43 years.

On average, respondents from substance use services reported spending just over half their time (53%) in direct contact with people attending the service while those working in hospice settings reported an average of 66%. However, for both groups there was a wide range with some spending very little time with people and others almost all their time with people accessing the service.

Similarly, and across survey respondents from both substance use and hospice settings, the number of people with whom professionals reported working varied widely ranging from none to 50 per day, although on average, substance use respondents reported working with about six people per day and hospice respondents reported an average of 10 people a day. Most people in both services felt they had good or moderate opportunities to build relationships with people and/or their families.

As might be expected in both types of service the amount of time spent with people with experience varied with the respondent's role, with practitioners reporting more time with them, and better opportunities to build relationships with them than did managers. Interestingly, administrators in substance use services reported the highest amount of time spent with people accessing services. In both types of service, better opportunities to build relationships were associated with working in either a ward/residential setting or community- or home-based outreach work rather than office or clinic-based setting.

Table 2.1: Demographic profile of participants

	Surveys		Focus groups (7 groups, 43 people)		Interviews †	
	SU (n=41)	Hospice (n=72)	SU (n=19)	Hospice (n=21)	SU (n=6)	Hospice (n=4)
Gender:						
Female	78%	97%	61%	83%	66%	100%
Male	22%	3%	39%	17%	33%	-
Age group						
25-34:	22%	12%	11%	8%		
35-44:	14.5%	21%	16%	8%		
45-54:	41.5%	36%	47%	17%		
55-64:	22%	23%	21%	58%		
65+	-	8%	5%	8%		
Ethnicity						
White British	90%	96%	79%	92%	100%	100%
Other**	10%	4%	21%	8%		
Religion						
None	46%	23%	Not recorded	Not recorded		
Catholic	14%	10%				
Other Christian	30%	55%				
Atheist	5%	10%				
Other***	5%	2%				
Employment						
Employed	90%	82%	95%	100%	100%	100%
Volunteer	10%	11%	5%			
Bank/Casual	-	6%				
Consultant	-	1%				
Job role						
Admin	10%	-	-	-	-	-
Managerial	15%	10%	-	-	75%	66%
Practitioner:*	75%	82%	100%	100%	25%	33%
Support	-	8%			-	-
Mean time in practice area (range)	8yrs 8mths (6m-26yrs)	12yrs 8 mths (1m-43yrs)	8yrs 8mths (1-20 yrs)	7yrs 1mth (1m-24yrs)	-	-

* Practitioner includes substance use support workers and health care assistants. Managerial includes senior practitioners in substance use services. ** Other includes, Indian, Pakistani and African-Caribbean. *** Other includes Buddhist/Sikh/Jewish.

† Roles include, service managers/head of service, specialist complex case work, leading specialist substance use projects, social work and medical consultant

2.6 Summary

This was a mixed methods study which focused on the experiences of professionals working in either substance use services or hospices when working with people who had both end of life and substance use needs. The study used a self-completion survey, focus groups and individual interviews to:

1. Access the views and experiences of a range of health and social care professionals in delivering end of life or substance use care to individuals and their family members, friends and carers (hereafter families) where people experienced both issues.
2. Assess professionals' attitudes towards supporting people with problematic substance use and chronic or terminal illness.
3. Establish the challenges and opportunities professionals face in supporting people with problematic substance use and chronic or terminal illness?

Participants across all three data collection methods included all levels of staff and some volunteers in both practice settings. Relatively low numbers prevented detailed comparative statistical analyses but numeric data were analysed using descriptive statistics and template analysis was applied to narrative data.

In terms of presenting the findings from the data, chapter 3 provides an introduction to the main issues considered in the study by discussing the findings from the survey which concern the extent and nature of professionals' experiences with the 'other' issue and assesses their confidence in, and attitude towards, working with people who have both end of life and substance use needs (objectives 1 and 2). Chapters 5-10 address objective 3 in thinking about challenges facing professionals when working with this group of people. These chapters draw on the qualitative data from the interviews and focus groups to explore professionals' perspectives on a range of challenges at individual, practice and systems level, with particular focus on working with family members, talking and asking about substance use, and pain management and prescribing.

PART TWO:
FINDINGS FROM THE SURVEY

Chapter 3. Findings from the survey of hospice and substance use professionals

We begin this consideration of professionals' experiences of working with people who have both substance use and end of life care needs by exploring the findings from the survey. The survey had three substantive sections, alongside demographic and practice experience variables. The three main sections were:

- Experience of working with 'the other problem'
- Experiences of working with 'the other service'
- Knowledge and confidence in working with 'the other problem' and perceived training needs.

Despite the survey having both open and closed questions, the data resulting from it are inevitably limited by brevity and lack of depth. Nevertheless, these data provide an opportunity to compare side by side responses from both respondent groups to explore aspects of experience. We begin here by examining professionals' perceptions of the ease of identifying the other issue and what sort of factors help recognition. We then move on to explore the extent to which professionals in both types of service encountered 'the other problem'. Where applicable we draw on data from the individual interviews and the focus groups.

3.1 Awareness or recognition of 'the other issue'

The first section of the survey contained a series of questions about recognition of 'the other issue'. About three-quarters of survey respondents from substance use services (n=30, 73%) felt they would be aware of the physical health needs of their service users and the remainder felt this might be true sometimes. Almost all respondents from substance use services reported thinking that when people needed palliative or end of life care, their poor health was related to their current or past drug or alcohol use (98%, n=40) and that these sorts of concerns were discussed within their teams.

Among hospice respondents, about 57% (n=41) were sure that they would usually be aware of a person's drug or alcohol problems, with a further 39% (n=28) indicating that they would 'sometimes' be aware and 86% (n=62) reported having thought that a person's condition might be associated with current or past substance use.

Both groups of respondents were asked to indicate how easy they thought it was to decide when a service user had 'the other problem'. As shown in figure 3.1, the majority of both groups thought this was not easy. Responses indicate that a slightly higher proportion of substance use workers found it difficult to identify when poor health signalled impending end of life than hospice workers found it to identify problematic substance use (46% of substance use professionals and 32% of hospice professionals respectively). Relatively few in either group reported finding it easy to identify the 'other' problem.

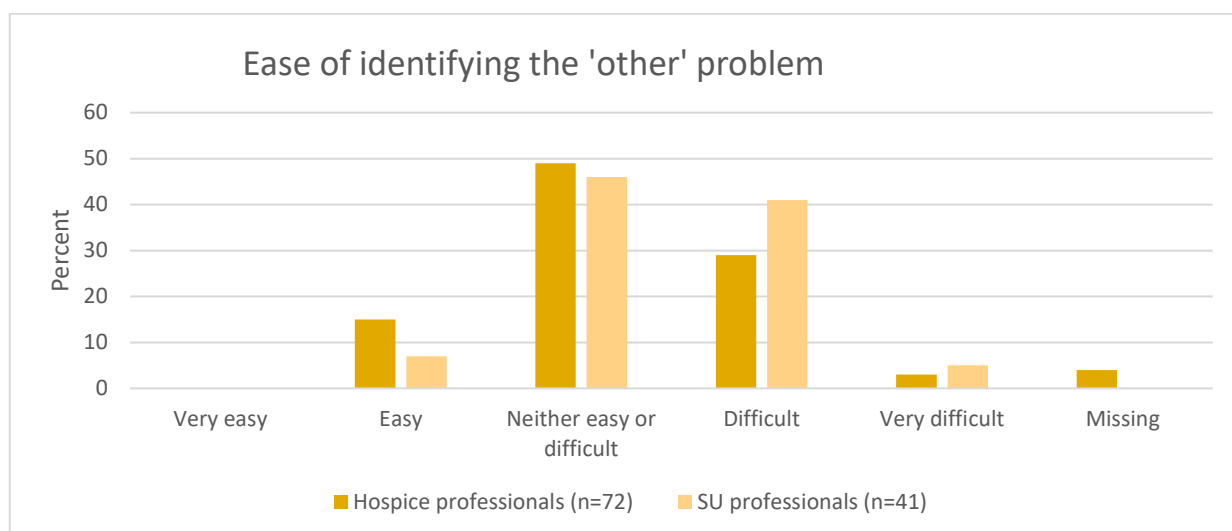


Figure 3.1: Ease of identifying the 'other' problem

The survey for respondents from substance use services were asked an open question about what sort of things made them think someone was nearing end of life. Their responses included:

- noticing physical signs of ill-health (coded 33 times), particularly signs and symptoms of alcohol-related liver disease
- poor mental well-being was also mentioned by several respondents (coded 9 times) as was deteriorating mental capacity (coded 5 times)
- other services, particularly GPs, sharing information about a person's health status (coded 10 times).

Some respondents also mentioned family members or carers, who could both be a source of information but might also increasingly struggle to cope.

Hospice workers, who were asked what sort of things made them think people might have substance use problems, also mentioned information from other services being useful in helping them to determine whether substance use problems might be an issue, and they recognised the concern of family members, carers and friends. There was mention too of people sharing information directly about their substance use problems but also one or two statements concerning the reliability or truthfulness of this information.

Especially noticeable among the responses of hospice workers were the references to behaviour, most notably aggressive behaviour, which was not as evident in the responses of substance use workers. Hospice staff also relied on their own observations of signs of drinking in particular, in the person or their environment, and some made links with deprivation and chaotic living conditions. Some of the responses of the hospice workers also identified some of the challenges that substance use can raise in the context of end of life or palliative care. These included people's ability or willingness to comply with treatment plans, the difficulties of disentangling whether symptoms were related to substance use or their health condition and providing effective pain control.

Disengaging with services was noted in both substance use and hospice workers responses as a sign that substance use might be an issue, as was a tendency for people to approach services only at a point of crisis.

Of course, identifying that a person with problematic substance use may have serious health problems, or that a person with palliative care needs may have substance use problems ultimately relies on professionals asking them about the 'other' issue. This is discussed further in part three of the report where practice challenges are discussed.

3.2 Extent and nature of encounters with the 'other' issue

In terms of the extent to which respondents had actually worked with people who experienced these overlapping problems, figure 3.2 shows that, in their current role, hospice workers had encountered more people with 'the other problem' than had substance use professionals. Thus, while 64% of hospice professionals (n=46) had worked with three or more people with overlapping issues, the same was true for only about 10% of substance use professionals (n=4).

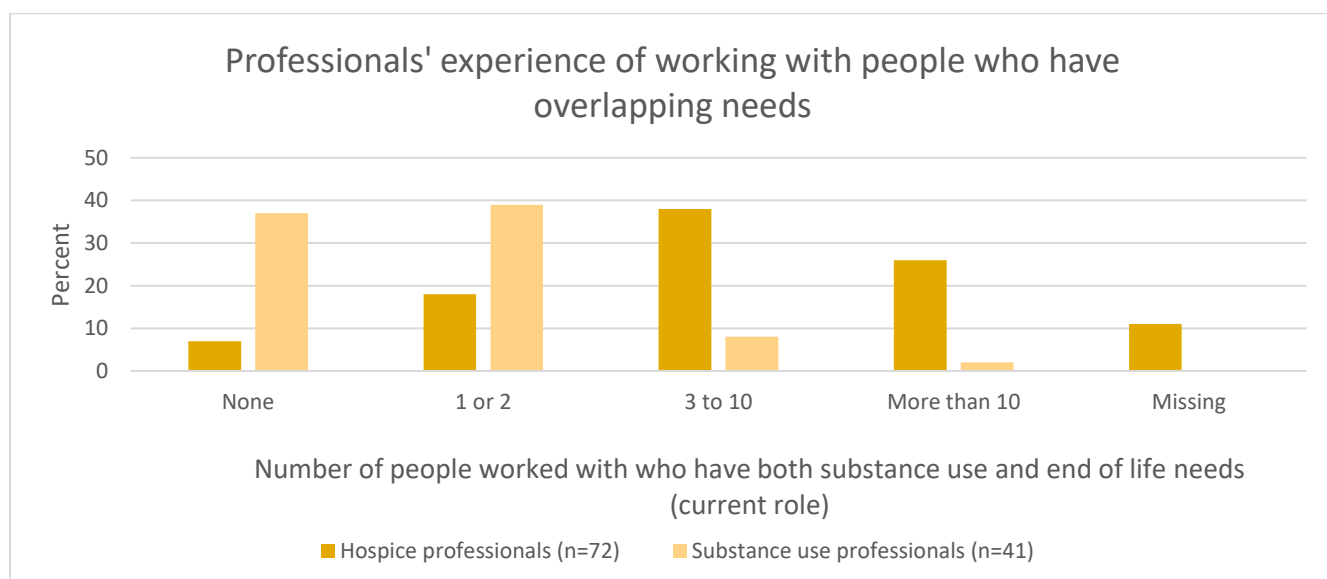


Figure 3.2 Experience of working with people with problematic substance use and end of life care needs for hospice and substance use professionals

Where respondents had worked with people experiencing both issues, 56% of substance use workers (n=22) reported this was mostly issues with alcohol and 22% (n=9) indicated that different types of substance (alcohol, illicit and prescription drugs) might be involved for different people. Experience for hospice professionals was different; half of hospice respondents (50%, n=34) reported having worked with people using different types of substance and 35% (n=24) had worked with people whose problems were with alcohol.

3.3 Extent and nature of encounters: qualitative data

The qualitative data also provided information and context on the frequency with which the different professional groups encountered the 'other' issue. Data were coded to this theme from five of the seven focus groups, and all 10 individual interviews. Three themes were developed from the coding process.

- Patterns, trends and impact of encounters (10 sources, 16 coded extracts)
- Frequency of encounters (5 sources, 16 coded extracts)
- Examples of encounters (7 sources, 35 coded extracts)

These are illustrated in figure 3.3:

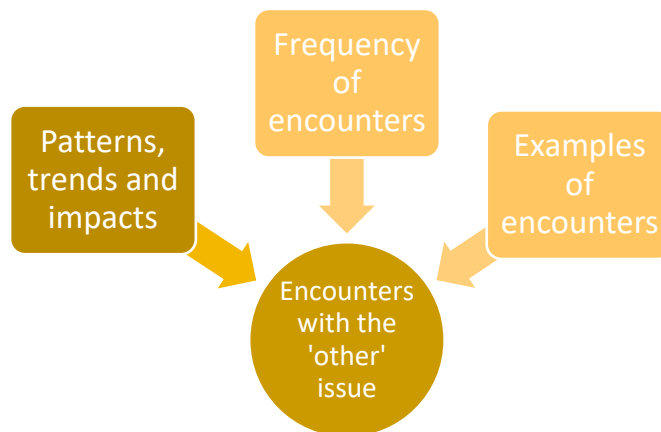


Figure 3.3 Three key themes relating to extent and nature of encounters with the ‘other’ issue

A fourth theme included at this point was generated from interview data only in response to a direct question about experience with hidden populations (8 sources, 11 coded extracts). Each of these themes are discussed below.

3.3.1 Patterns trends and impact of encounters

Substance use professionals’ perspectives: Rising numbers and increasing need

The data from substance use professionals suggested an increasing number of cases where they were working with both issues and an increasing complexity of need. For example, an increase in drug-related deaths was noted by one interviewee, along with a spike in referrals from hospital in relation to people who were very ill as a result of alcohol-related issues [Substance use professional - interviewee]. Another interviewee explained that while their service did encounter overlapping issues, it was in working more closely with hospitals that really brought home how unwell people could be:

Obviously people have died along the way but it wasn’t until we went to work at the hospital where you’re absolutely smack bang face on, I think it’s a bit of a shock to be honest, to actually see them.

[Substance use professional - interviewee]

Both focus groups and individual interviews in substance use services drew attention to the links between smoking crack-cocaine and developing chronic obstructive pulmonary disease (COPD).

However, participants also made the point that illicit drug use might more often be associated with sudden death as a result of high levels of risk taking. This could mean “something could happen to them that may not be intentional”. Alternatively, people may deliberately self-harm, that is “people who have a history of suicide attempts, very, very many suicide attempts” [Substance use focus group].

In contrast, it was noted that alcohol related ill-health might co-exist with multiple physical health problems:

I think we’re all getting more of a generation of clients, particularly alcohol clients, who are coming in later in life who do have several physical health complications and there’s a very high risk that if something doesn’t happen quickly, and even if something does happen quickly, i.e. you’re able to get them into detox, there’s still a chance that they may not be around for that much longer. [Substance use professional - focus group]

As will be seen in later sections of this report, the issue of complex health and social care needs among substance users at the end of life, particularly when considered in the context of rising numbers, is very important, and speaks to concern about levels of unmet need and demand on services.

In this sector of work, [...] particularly in our work with both complex needs ... End of life care is a regular occurrence for us. ... But I don't think that end of life care services are set up particularly well to deal with people with drug and alcohol problems that then result in other major issues. There are 500 people on the liver specialists’ pathway for cirrhosis, end stage for cirrhosis, in [this town] alone. [Substance use professional - interviewee]

Another substance use interviewee thought that it was unlikely that that this issue would resolve itself, rather the opposite:

I can’t see this population of substance misuse and end of life, I can’t see it stopping and we’re going to have the binge drinkers, the younger ones are going to be coming through soon with the same kind of health damage ..., they’re just going to keep coming through, it’s not going to stop.
[Substance use professional - interviewee]

Hospice professionals’ perspectives

Although the survey responses indicated more frequent encounters with the overlapping issues for people working in end of life care than was true for the substance use professionals, the focus group discussions suggested experience was mixed, indeed in one EOL focus group participants felt that they just didn’t see people with substance use problems:

Having said that, I don't think we get a lot of and I think that's because they all just go in the hospital and die in hospital. [Hospice professional - focus group]

One of the individual interviewees also emphasised this point, but also raised the question of whether hospice staff would always be aware of peoples' substance use problems:

... we just don't really know how many people ... you know, are we missing something in terms of are there people that we see that we don't know have got a drug and alcohol history or that might be struggling with something, do you know what I mean? [Hospice professional - interviewee]

Looking across the hospice focus groups, experience varied according to which part of the service participants worked in and where the service was located. Distinctions were drawn between experience on an in-patient unit and experience in the home or community setting, with participants expressing the view that problems with substance use were more likely to be seen when working in the community rather than in-patient units. This was understood in the context of people being quite ill and unable to consume substances by the time they were admitted. However, there was some discussion about people sometimes arriving at day units smelling of alcohol. For those working in the hospice setting (as opposed to the community) alcohol was perceived to be a more common problem than illicit drugs.

Comparisons were also drawn in terms of geographical location with both alcohol and illicit drugs problems perceived to be more common in city centres. Indeed, for some participants it was quite a regular occurrence, related to the location of their work being in areas with high concentrations of social deprivation:

I'd say in the geographical area that I cover, it's a fairly frequent occurrence. [Hospice professional - focus group]

That said, some participants reflected that substance use, and alcohol use in particular, may be just as prevalent in more affluent areas:

I'm not being disrespectful, but people presume because they've probably got more money and a better education, but actually there's a crossover I would say... "We're just going to have a little aperitif before dinner." It's half past 10. And I'm not exaggerating, it does happen. And that's fine, that's up to them, isn't it? [Hospice professional - focus group]

The individual interviews with hospice staff confirmed that the numbers of people with problematic substance use at the time were relatively small but recent increases had been detected by one interviewee:

I think there's huge amount of unmet need, we certainly have seen, I think in the last year we've definitely seen more patients who have a history of drug dependency than we have done in the last five years previous to that and I think some of that is about the ageing population ...
[Hospice professional - interviewee]

3.3.3 Frequency of encounters and examples of encounters

The discussion above about patterns of experience gives some sense of the frequency of encounters for each group of participants. In general, substance use professionals taking part in the qualitative parts of this study had significant experience of working with both issues. However, this may reflect the fact that both of the substance use agencies participating in this study had experience of developing and delivering specific projects (one hospital based, the other community based) which would have increased the likelihood of contact with older and/or ill substance users in particular.

As previously mentioned, hospice professionals' experience of working with substance use was varied depending on location and job role but there was a definite sense in the data that this was not perceived as a frequent occurrence, with some staff giving examples of working with these overlapping issues more in previous nursing roles in the community.

Participants from both professional groups gave examples of a range of cases they had worked with which included both older and younger age groups, and they spoke from both professional and (some) personal experience.

Service engagement with 'hard to reach' groups

In relation to encounters with 'the other issue' we specifically asked interviewees about their services' engagement with 'hard to reach' or 'hidden' groups. The majority of people discussed homeless people in their response to this question – quite probably because we had given this as an example in our question. Ethnicity, for example, was mentioned by only one person (an interviewee from a substance use service). People from minority communities are among the groups identified as under-served by EOLC services (Calanzani et al, 2013).

The needs of people with mental health difficulties and, to a lesser extent, those in prisons were discussed briefly by substance use professionals, but not by hospice staff. Homeless people, particularly rough sleepers were recognised as a group who often did not access services and one interviewee stressed that substance use services tend to have few referral criteria and would be open to working with this group. Another interviewee described how their service had helped a couple of people living in hostels with housing but explained that, on the whole, the CCG they worked with did not cover the main homeless areas of their town. Rather the group this service focused on were vulnerable individuals with high levels of need – but housed:

I think for us, the population that we've been looking at is those that...
[have] been using alcohol for so many years, they are stuck in their homes, they are isolated, they have very little confidence, poor social skills, high levels of social anxiety and that would summarise our population in the main.

[Substance use professional - interviewee]

Another interviewee highlighted how it could be difficult to work with people with mental health problems if they were abusive:

... a lot of people with mental health issues, especially that maybe behave inappropriately or are quite abusive, then people don't work with them, so they get lost along the way as well. [Substance use professional - interviewee]

An important issue in relation to expanding services into harder to reach populations was that of making meaningful links with organisations already working in that sector. An interviewee from one hospice highlighted the need for services to work together to address need because, while they were getting occasional referrals, they were not getting the amount anticipated:

We know that we're not getting the referrals, and we do know that often that end of life care, particularly with liver failure, it can be quite traumatic and it can be quite sudden, so we've got someone interestingly who came in on the ward last week for that reason, and ended up dying with us, so we are getting those referrals. [Hospice professional - interviewee]

This issue of referral pathways, attitudes and joint working is something that is discussed in more depth in chapter 10.

3.4 Experience of working with the 'other' service

The second substantive section of the survey explored the extent to which substance use and EOLC services worked together when people faced both problematic substance use and end of life care. The survey contained four closed and two open questions on this topic to establish the level of need for these services to work together, ease of access to the other service, and gaps in service provision.

Survey responses indicated that for hospice professionals:

- Just under one fifth had worked with substance use services (n=14, 19%), although a further 14 would have liked to do so.
- Of the 14 who had worked with substance use services, nine had done so to support a person and five to support both person and their family.
- Of the 14 hospice workers with experience of substance use services, six thought that substance use services were able to meet the needs of their patients, seven thought this was achieved in some ways, and just one person thought the service did not meet needs at all.

Ease of accessing substance use services was explored using a sliding scale (-10 = very difficult to +10 very easy). The experience of hospice workers was very mixed. The average score was .75 (range -10 to +7). Seven of 17 people (41%) who expressed a view indicated

that access was neither easy nor difficult, but three people rated access in the 'difficult to very difficult' range.

Hospice workers felt access was complicated by their lack of local knowledge about services and how to refer. The point was made by one respondent that the internet had made it much easier to find out about local resources but, as indicated by another, information needs to be up to date. Gaps in substance use service provision, as identified by hospice workers, were mainly to do with response times although there was recognition that services were busy. One respondent commented that because the person was palliative the service was able to see him quickly. Other issues identified included the substance use service not being able to see people in their own homes, sharing of information between services and joint planning of support in an ongoing way:

More liaising /support [from substance use services]. Not just feeling the person is now palliative and withdrawing support. Need amalgamation and joint care planning. [Hospice survey respondent]

From the perspective of substance use workers, 13 of 40 (32%) indicated that they had either worked with EOLC services (n=6) or would have liked to do so (n=7). Again, the reasons for wanting to refer involved their seeking support for the person in three cases, a family member in one case, and both person and their family in four cases. Of those who had experience of referring to EOLC services, or trying to refer, three thought EOLC services were able to meet people's needs, five thought this was true in some ways and two thought they were not. Three people did not express a view.

In terms of ease of access to EOLC/palliative care services on the scale from -10 to +10, the average response was 1.74 across substance use workers, with a range from -8 to +8. Of 14 responses, three were in the 'difficult/very difficult' range, five indicated 'neither easy or difficult' and six rated access as easy to very easy.

Issues identified in relation to accessing EOLC/palliative care services were rarely to do with information. Indeed, there were comments that suggested access could be very straightforward with a single point of contact. What was highlighted however, were issues about 'a lack of a clear pathway' and whether these services were available for people with substance use problems and/or related illnesses:

Health/mental health workers do not want to work with clients with addictions. Sees them as too problematic. [Substance use survey respondent]

3.5 Knowledge and attitudes

One of the aims of this strand of the research programme was to explore the confidence and attitudes of professionals towards working with the 'other' issue. We felt it was important to examine individuals' perceptions of their level of knowledge in relation to working with 'the other problem' and their attitudes towards working with people who have both substance use and end of life care needs because understanding these factors can help

to identify areas where different professional groups may benefit from training and professional development opportunities.

As previously discussed (see chapter 2), two tools were used in this part of the survey, one for each group of professionals. Hospice respondents were asked to complete questions about working with people with substance use problems (SAAPPQ), while questions for substance use specialists focused on their work with people who had life-limiting conditions or palliative care needs (our shorthand for this tool is the LLIPPQ). This section of the survey contained the 10 items of the SAAPPQ along with an additional five questions drawn from the SAP. Each tool comprised 15 statements and included the five 'domains' identified for the SAAPPQ. We report here in line with domains as identified for the SAAPPQ (and borrowed for LLIPPQ) and the focus of these is as outlined in table 3.1:

Table 3.1 Domains and structure of the Short APPQ/LLIPPQ

1. Role adequacy	2 questions about perceptions of own knowledge and working with the 'other' issue
2. Task-specific self-esteem	Two questions about sense of efficacy in working with the 'other' issue
3. Role Satisfaction	Two questions about sense of enjoyment and reward in working with the 'other' issue
4. Role Legitimacy	Two questions about perceptions of having right to ask about the 'other' issue
5. Role Motivation	Two questions about level of interest in working with the 'other' issue
6. Therapeutic commitment	An overall score indicative of attitudes towards working with the other issue (motivation, satisfaction and task-specific self-esteem)

The resulting tools contained both positive and negative items presented on a Likert scale. For ease of interpretation, these were coded so that higher scores indicated agreement with the statement. (1 = definitely disagree, 7 = definitely agree). Three negatively worded items were subsequently reverse coded meaning that for all items a low score indicates a negative attitude.

Table 3.2 below provides the average scores (means and medians) for each of the seven domains of the tool AAPPQ/LLIPPQ. Scoring is such that 4 indicates 'neither agree or disagree': i.e. a neutral response and values above 4 indicate more positive attitudes, on average, for the group.

Table 3.2: Average (median) scores knowledge and attitude domains for both service groups

<i>Average domain scores (SAAPPQ/LLIPPQ)</i>	Hospice respondents SAAPPQ (n=62) Median	SU respondents LLIPPQ (n=33) Median
<i>Role adequacy</i>	3.75	4.00
<i>Task specific self-esteem</i>	5.00	5.00
<i>Role satisfaction</i>	4.00	4.00
<i>Role legitimacy</i>	4.75	5.00
<i>Role motivation</i>	4.50	5.50
<i>Therapeutic Commitment</i>	4.75	4.67

Note to table 3.2: results reported for only those respondents providing a complete set of data for this tool

Thus, as can be seen in table 3.2, the average (median) scores for role adequacy and role satisfaction are at, or below, four for both participant groups and represent the lowest average score for any domain. This suggests that, for the groups as a whole, there was some disagreement with the positively worded statements about levels of knowledge regarding either end of life or substance use issues. In other words, the responses suggest that people did not feel they had adequate levels of knowledge about the ‘other’ issue (adequacy) and that they did not find a lot of satisfaction or reward in working with those issues.

All other scores are in the positive (i.e. above 4) suggesting some degree of motivation to work with ‘the other issue’ and a sense of legitimacy and self-efficacy in the role. However, for the most part, the average scores for these domains remain fairly close to the neutral point (score of 4). This could suggest some ambivalence or a lack of experience or simply that respondents had not given the issue a great deal of prior consideration. However, as will be seen in later chapters, the qualitative data suggests positive attitudes and motivation for working with this group of people, regardless of substance use or hospice specialism.

As is clear from table 3.2, the only domain in which the median score for the two professional groups is very different is in role motivation, where the average for substance use professionals indicated a more positive response than was true for hospice professionals

3.6 Summary

This chapter has focused on hospice and substance use professionals’ experience of working with people experiencing both problematic substance use and end of life care needs, as reported in their responses to survey questions. It has also drawn on some of qualitative data from the interviews and focus groups to provide a more in-depth picture of some of the issues which are not addressed again in this report.

Overall, while most substance use professionals felt they would be aware of health issues for the service users and most hospice staff felt they would be aware if a service user had substance use problems, very few respondents in either group found it easy to definitively identify the ‘other’ problem.

The survey found that hospice professionals reported working with more people with both issues than did their substance use colleagues but were aware that they only saw a very small proportion in comparison to hospitals. For hospice professionals, frequency of encounters varied according to whether they worked with in-patients or in the community and the characteristics of the location they worked in. Analysis of some of the qualitative data identified that from substance use professionals' perspectives the numbers of people with both substance use and end of life needs were increasing and both groups indicated a great deal of unmet need. Discussion about working with 'hard to reach' groups flagged the challenging circumstances of many people who have these overlapping needs and issues related to identification of end of life and patterns of referral into end of life services.

In the experience of both groups of professionals it was mainly problems with alcohol (as opposed to other drugs) that was associated with the end of life need. In terms of joint working, only a small percentage of professionals from each sector had worked with or referred to the 'other' service. There were mixed experiences from those who had about whether or not the other service had met the needs of the person referred. The lack of a clear pathway was highlighted for people needing or wanting both services.

Exploring professionals' knowledge and attitudes towards working with these overlapping issues, using an adaptation of a recognised measure, indicated that both groups of professionals felt they did not have an adequate level of knowledge about the other issue. Both were slightly more positive about their sense of legitimacy in asking people about the 'other' issue, and their sense of satisfaction and motivation in working with this group and that they could find adequate support if needed. That said, scores, though positive, were still quite close to the neutral mid-point.

PART THREE:
PRACTICE AND SERVICE LEVEL CHALLENGES

Chapter 4. Practice and service level challenges: an overview

The previous chapters have established a picture of the extent to which professionals worked with individuals nearing the end of life who have histories of problematic substance use and their confidence in undertaking this work. This section of the report moves on to consider the major aim of this strand of the research which was ‘to establish the challenges and opportunities professionals face in supporting people with problematic substance use and chronic or terminal illness?’.

The chapters in this section rely predominantly on the qualitative data from focus groups and individual interviews. As mentioned in the methods chapter, the analysis of qualitative data from both these sources followed a ‘template analysis’ process involving the identification of ‘a priori’ themes (or topics) and subsequent grounded, or bottom up, coding to the a priori themes whilst also capturing new top level themes in the process.

The overarching *a priori* theme, or topic code, relevant to the following chapters was ‘practice challenges’. Other *a priori* topics included ‘asking about the ‘other’ issue’, ‘joint working with other agencies’, ‘policy and commissioning’; ‘medication and pain management’. The inductive (grounded/bottom-up) coding then sought to identify additional themes as a result of a close reading of the data. In total 433 individual coded extracts were developed from the data. Inevitably, once the inductive coding was underway there was some overlap between these categories with some issues appearing, in different guises, in more than one category. Subsequently, these themes were then condensed into thematic clusters thereby reducing the mass of coded extracts to key overarching themes that speak most closely to the aims of the research. This analytic process also demonstrated the strength of particular challenges, specifically, asking or talking about the other issue, managing medications and prescribing practice, and working with families.

Figure 4.1 (below) illustrates the main themes under the topic of practice challenges and each chapter in this part of the report will begin with a graphic illustration of the themes and sub-themes within each chapter.

Chapter 5 presents the findings relating to challenges for people with experience, as recognised by professionals, and chapter 6 considers challenges for professionals in responding to those needs. Chapter 7 moves on to reflect on issues around asking about ‘the other problem’; chapter 8 focuses on medication issues, chapter 9 brings family issues into play and chapter 10 relates the findings concerning system level challenges.



Figure 4.1 – Key themes relating to practice challenges

Chapter 5. Challenges for people with experience

This chapter presents the themes relating to *professionals' perspectives* of individuals' experience, the challenges people faced, and the challenges they faced as professionals trying to meet the needs of this group of people. In total these themes drew from 65 coded extracts and 14 sources.

Figure 5.1 below illustrates the sub-themes located within this thematic cluster:



Figure 5.1 - Key themes within the cluster ‘Challenges for people with experience’

5.1 Individual behaviour, experience and lifestyle choices

In focus group discussions and individual interviews professionals talked a good deal about people they had worked with, highlighting some of the challenges those people faced and how their circumstances and experiences might impact on their end of life experience. Data relevant to this coding category were grouped under the sub-theme of ‘individual behaviour, experience, and lifestyle choices’.

Within this sub-theme were two coding clusters, these related to:

- Complexity of needs (including the physical, mental and psychological impact of substance use and life-limiting illness) and sporadic attendance/engagement with treatment
- External stigma and negative attitudes toward this group of people

5.1.1 Complexity of needs and sporadic engagement with treatment

In the course of the data collection, the professionals reflected on the challenges faced by people with experience of problematic substance use and end of life care needs. A major thread through all data sources was the complexity or multiplicity of needs with which this group of people often presented.

Both sets of professionals were aware that this group of people will usually have multiple co-morbidities, the effects of which might be either accentuated or hidden by their substance use. Participants perceived that this group would typically have a complexity of both physical and psycho-social needs, including housing and financial difficulties, estrangement from families, and social isolation. There were numerous examples given of people being repeatedly admitted to hospital for a variety of reasons. Professionals also

reflected on the fact that many people may have long histories of engaging and disengaging from all sorts of services, including prematurely discharging themselves from hospitals.

I think the other thing is that often these patients find it very difficult to use healthcare settings, they fall under two categories, [one group being those] who've had perhaps quite negative experience of healthcare and have felt judged and not necessarily supported. And so they're quite suspicious and find it very difficult to trust that the healthcare providers have their best interests at heart, [Hospice professional - interviewee]

Reference was also made to the fact that this group often live what was termed a 'chaotic' lifestyle and this, alongside co-existing physical (e.g. mobility problems) or psychological difficulties (e.g. agoraphobia), can mean they are likely to find it difficult to manage attendance at medical (or other) appointments. In addition, substance use is frequently associated with a breakdown in relationships with family and friends and both groups of professionals were aware that this group of people might often die in isolation.

Participants from substance use services highlighted the social isolation and loneliness experienced by many of the people they worked with, and described how this could result in people being particularly emotionally dependent upon support workers – leaving staff with a great sense of responsibility for their wellbeing:

The thing that strikes me most about people is the loneliness and the isolation. And I've worked with a couple of people, probably about three or four people in the last six months that have died at home on their own. They've been in hospital, they've been diagnosed with predominantly liver complaints, physical health complaints and have deteriorated and deteriorated until they've passed away - usually on their own. So I think there's a real, the thing that strikes me is I suppose is the feeling of hopelessness that clients have.
[Substance use professional - focus group]

This suggests a need for additional emotional support for professionals to cope with both the loss and the feeling of responsibility. This is discussed further in chapter 12.

One hospice professional recounted trying to get someone in the community to go to the hospice but he refused to go. This could be explained by the experience of the substance use professionals who said that people with substance problems fear services and the labelling they receive. However, other professionals explained that some people worried that hospices would not offer an environment that would support continued substance use.

5.1.2 External stigma and negative attitudes towards this group of people

Professionals in this study reflected on the circumstances that often lead to problematic substance use and society's lack of willingness, generally, to see beyond the surface. The following extract from one focus group discussion illustrates this perception:

They often ... are victims of something that's happened to them but towards the end of their life, they're almost demonised for their behaviour. But they did originally start off as people that society would have real sympathy with, through sexual abuse, stuff that's happened to them as a young adult or child, which has then led them into adulthood and often being quite demonised for their behaviour. But really, they are quite sad people that something terrible has happened to them, but society doesn't look at what originally started that off. [Substance use professional - focus group]

Professionals recounted many examples of people receiving poor treatment, particularly in primary and acute health care settings. This resulted in people discharging themselves prematurely and refusing to go back in to hospital until they were at crisis point or not presenting to primary care services until their health condition was intolerable. Although sometimes premature hospital discharge was described in terms of people wanting to continue to use substances and being unable to in hospital settings.

Professionals described how people were also exposed to stigmatising attitudes and, at best, a lack of recognition of their needs by a range of agencies. Many stories were told of people's health needs being overlooked because of the substance use and further tests had not been done prior to their deaths due to an assumption that the substance use was the issue or that the individual was just wanting pain medication.

We got a referral from a hospital team and it was a lady, she was described as an ex IV user. What was really sad about this lady, because she had that label, and that's 20 years since she's been an IV user.... She's not using, but she's still got the label. The sad thing was that she presented at the doctor's several times, and it was assumed she just wanted pain killers, and nothing was done, it was ignored. ... They just kept assuming she was coming back for pain killers. Actually, it turns out this lady, she's riddled with cancer and it was only diagnosed when there was brain involvement. Somebody at last actually listened to her. She's only [in her 40s]. So, when I did the second visit and her sister was there, they were really, really, angry and hurt. They were saying if she hadn't had that on her record, she would have been treated better. [Hospice professional - focus group]

Other examples were also given whereby someone's methadone use and someone else's alcohol use were 'covering up' the symptoms of serious illness.

5.2 Summary

Overall, the data from this study suggest that people who have a history of substance use may face particular challenges when they are nearing end of life. Their physical health is likely to be marred by multiple conditions, which can impact on activities and emotional well-being and impact on people's ability to engage effectively with services that require attendance at appointments. Having a history of substance use on a person's medical record was perceived by professionals in both hospices and substance use services to be linked

with stigmatising responses from primary and acute care, even when the substance use was a long time in the past.

Chapter 6. Challenges for individual professionals

As outlined in chapter 4 (figure 4.1), the practice challenges data were coded to six thematic clusters including challenges for individual professionals and practice. Within this cluster were two key themes were drawn from 98 coded extracts and across 17 sources:

- Meeting the needs of people in the service
- Working with other services

These two key themes contained five sub-themes between them. Figure 6.1 (below) illustrates the themes in this cluster which will be discussed in turn.

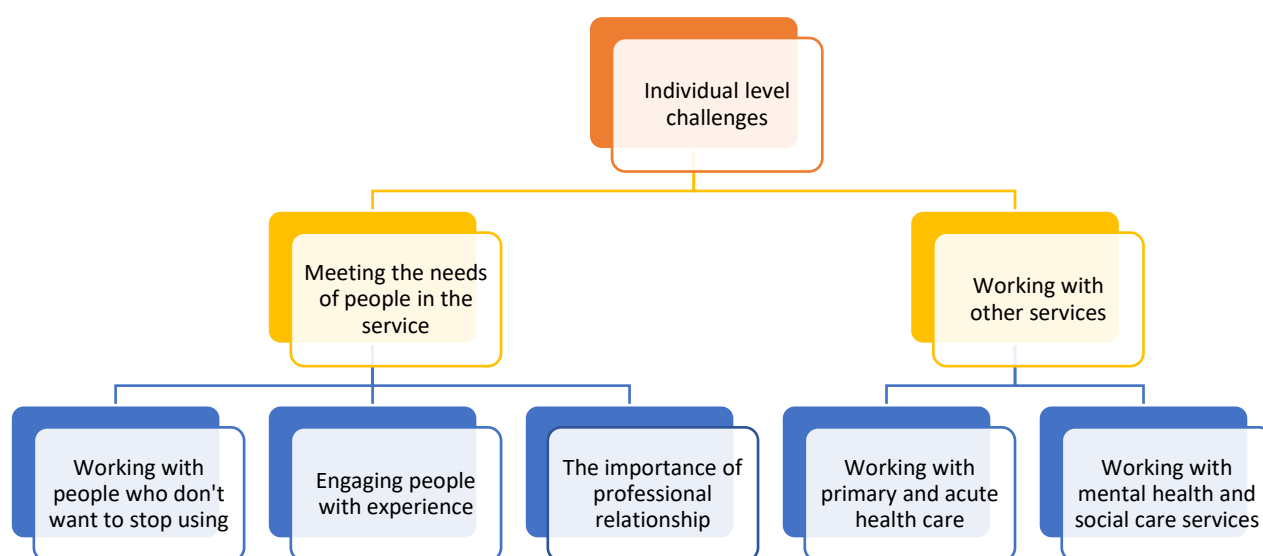


Figure 6.1 – Themes and sub-themes identified in the cluster ‘Challenges for individual professionals’

6.1 Meeting the needs of people in the service

The sub-theme of meeting the needs of people in the service encompasses a series of practice challenges including:

- Working with people who don’t want to stop using
- Engaging people with experience and the need for holistic approach
- The importance of a professional relationship

6.1.1 Working with people who don’t want to stop using

One of the topics identified in the data as core to people’s complex and multiple needs was that some people with experience did not want to stop using substances despite being very ill. The hospice staff were aware that people had heard all the health warnings about the risks and dangers of substance use before. Therefore, it was not an appropriate focus of their care, particularly when people were very close to the end of their life. However, they

pointed out that people with current problematic substance use often faced a very rapid deterioration in their health prior to death. This could lead to shock for individuals (and their family members) who may have anticipated living longer, particularly if they had not been made aware of their reduced longevity (Ashby et al., 2018; Yarwood et al., 2018).

Some substance use professionals pointed out, however, that people who had used substances problematically, but who had low Liver Function Test results and showed no other health problems, had a false sense of security and feelings of invincibility. However, other substance use professionals believed it was more a case of people having a fatalistic attitude towards their futures:

Self-medicating in some respects, they're feeling really low and really rotten and they have problems and they've lost their family because of drinking and they've lost their job and they've lost the house and everything else, and some just say, I don't care, it will kill me but I don't care because what else have I got, I've only got my alcohol so I'll just carry on drinking.

[Substance use professional - interviewee]

It was also a challenge for the substance use group to move from a professional approach focussing on 'recovery' to one which focussed on end of life care. Similarly, the hospice staff spoke of traditional roles in health promotion about drinking or smoking, for example, not being applicable in end of life care practice.

There were people in both groups who identified the challenge of working with people who did not want to change their substance use. For the substance use professionals, it was expressed as frustration; wanting to improve the quality of life for people in their service or, for those who relapsed, their frustration at not seeing the outputs for the work they had put in. For the hospice professionals, their concern was more about the clinical implications of not knowing what someone was using in relation to medication management and understanding the impact on behaviour. They were not so concerned about the impact of the substance use *per se* on people's health, as this was a group of people who were at, or near, the end of their lives. Communicating the severity of the situation to the individual and family members who may be intoxicated and not hearing or retaining information was flagged as a challenge however.

6.1.2 Engaging people with experience and the need for holistic response

Another theme within the focus group and interview discussions was the importance of engaging people and being able to deliver a holistic response to meet their needs:

We do go to lengths to try and engage with clients because I've heard of some services where you'll get a referral, you'll try and contact once. If that person then doesn't either engage or respond, it's almost like, "Well, we've got too many other people wanting treatment and support, we can't spend time on chasing people all the time," so they'll then either discharge or not do anything with that person and then just move on. Whereas, we do deal with all referrals... We can't spend all our time chasing people up, but we will try and chase people up to try and engage

with them and obviously there's been an issue why they've ... been referred to the service so it's about looking at trying to engage as much as possible really. [Substance use professional - interviewee]

Participants noted that this group of people might be particularly reluctant to engage if they have had difficult experiences of health care previously. Professionals recognised practical barriers to engagement for people with experience too:

It's difficult, isn't it. It's also about availability and geography and travel and support to get to places and the fact that they're often not just physically very, very unwell but socially isolated, excluded and may not be receiving all the benefits that they require and a whole range of other things. Cost and time and support to get to places and manage appointments and all of that becomes really difficult. Then mobility becomes a real issue. [Substance use professional - interviewee]

The need to act in an advocacy capacity was also recognised by substance use specialists:

Being flexible about home visits, being an advocate, taking on the advocacy role, normally we'd want an empowerment role when people come to us in a generic alcohol service but I think actually, we've experienced that people just haven't got the energy, they haven't got the physical energy to fight battles all the time and we need to take on their case. So, I think it's the willingness to go there and do some of that that's possibly more of an advocate than an enabler, maybe. [Substance use professional - interviewee]

6.1.3 The importance of the professional relationship

Substance use specialists said the relationship they developed, or sought to develop, with people in the service was important to successfully engaging them in the service. One aspect of this was about respecting the person's choices:

I suppose the biggest challenge is whether the client wants to work with you or not. That's the biggest thing to get over, [...] - because a lot of the times we have referrals from GPs or family members, and then we go to speak to the clients and they'll say, "I don't know what you're talking about or stay out of my business and..." so that's like the biggest challenge to start with.
[Substance use professional - interviewee]

There was also a caution about the need to observe professional boundaries and the risk of people becoming dependent on their worker in the context of all the advocacy and support that substance use specialists can find themselves providing:

I think the problem is it's a risk of them then getting quite dependent on you, which of course we're finding now we're having to pull out [stop the specialist service]. There aren't many people like us that are willing to get their hands as dirty, so it's quite tricky pulling out when people's issues aren't completely resolved. [Substance use professional - interviewee]

Overall, the picture painted of a good service response is that it is person focused, with a holistic approach that is non-judgemental and, on the part of substance use professionals at least, includes the opportunity to undertake some outreach work and be flexible in the way they work. Services need staff who have the time to check on people to ensure they are safe, and time to accompany people to appointments for example, staff who are good at listening and able to help people cope with fear, guilt and shame.

However, such a response is time consuming, requiring liaison with a range of services to provide appropriate health and social care support. Despite the level of need, for both hospice and substance use professionals, reduced resources and funding resulted in limited time to give to people who needed support and was an obstacle to the depth of conversations they would like to have with them. For the hospice group, the time factor also related to what could be done or discussed given the limited time that people may have to live, with an acknowledgement that increasingly complex needs require more time to address.

6.2 Working with other services to meet individual needs

For the substance use professionals group, the challenges of stigma relating to problematic substance use (highlighted in the chapter 5) resulted in a struggle to get the right treatment for people and to negotiate and advocate with a range of health professionals. There was a strong sense from some substance use professionals that other services simply didn't want to work with people who use substances: that their needs were too complex and substance use services were the only service that offered support for this group of people. In the following quote, one focus group participant contrasted her usual experience of trying to access support from other agencies with a recent experience with the Macmillan nursing service:

I've just had an experience with the Macmillan nurses and I was absolutely....., Sometimes when we ring up services and say we've got somebody, you hear that [sighs] "I wish I'd not answered the phone", but with the Macmillan nurses, I was absolutely surprised at how good they were and how much it [the substance use] did not matter. Because sometimes we have to put our clients' cases forward and we tell, not white lies but we might not say it as bad as it is, because we know that they need the help and they're not going to get in if we don't.
[Substance use professional - focus group]

However, such positive examples were limited in the context of this study, and acute and primary care were particularly singled out for much criticism.

6.2.1 Working with primary and acute health care

The major challenges professionals faced in working with primary and acute health care services seemed to be related to professionals' attitudes to working with someone with problematic substance use and the inability of many people in this client group to work in the way health services are routinely delivered.

General Practitioners (GPs) were often criticised for being overly simplistic and dismissive of the health concerns of people with problematic substance use, particularly in failing to recognise (or overlook) symptoms or tending to blame health conditions on the substance use alone and there were stories of people not being treated for their pain because of the medic's suspicion that they were simply wanting more medication. As was seen in the previous chapter, even when someone's substance use problems were long in the past the label of 'ex IV user' was perceived as negatively impacting care provision.

A range of possible reasons for this ambivalent response from GPs was identified in the narratives of professionals, these included:

- an assumption that symptoms were due to the substance use rather than investigating possible underlying pathology,
- a suspicion that people complaining of pain were simply looking for more medication,
- a judgement about illness being self-inflicted and meriting a lesser response than a cancer diagnosis.
- embarrassment about asking about drinking as a possible cause of health issues,
- frustration on the part of medical staff that people don't stop using,
- people's behaviour in health settings when intoxicated (particularly aggression) and the tendency for premature self-discharge causing concern and frustration.

An additional challenge was the 'one appointment, one condition' principle operating in many GP surgeries, which is clearly limiting when people experience multiple co-morbidities:

...we're in this climate of one appointment/one condition and actually quite a lot of our clients have got several conditions, so it's not just liver disease, if only it was just liver disease, but there are lots of other things likely to be there as well. [Substance use professional - interviewee]

Other examples were given of GPs being more blatant about keeping people with problematic substance use away:

Well some GPs have put notices up. There's one that they don't prescribe diazepam or anything with ... [Hospice professional - focus group]

Acute care, and particularly where people had been an inpatient for a substance-related condition, was often criticised by participants. Hospital staff were reported as lacking compassion and having poor attitudes to relatives, for example.

I think a really important thing is sometimes our clients' experience of the treatment they receive in hospital, they want to discharge themselves, ... I've had clients who have received phenomenally poor, not medical care, but phenomenally poor inter-personal care. [Substance use professional - focus group]

I've got a client who's been in twice with severe pain from stomach problems and hasn't been drinking but has been forced to take Librium because they just see, "Ah, alcohol problem, pop the Librium in, detox them, get them out." So they're not actually addressing what are the health issues of those clients. [Substance use professional - focus group]

Thus, a range of factors were perceived to impact, potentially, on the way in which primary care and hospitals might engage in joint working for this group of people at the level of individual care. That said, not all experience was poor, some professionals reported positive responses from both GPs and hospital staff in individual cases:

I have been quite lucky with connecting the GPs and occupational therapy and connecting them all together, but I know other colleagues that have had difficulty with that. You know, and sometimes the attitude of the GP is, "Well, we've tried and tried over the years, I'm not going to bother anymore". Which is understandable, but the nature of addiction and then the health problems that come with it, that's how it is, that's how it works. [Substance use professional - interviewee]

But my experience of the consultants [has] been really good actually, and I've never, I've never seen a consultant be sharp or rude or abrupt to any of the clients. Even though they know that it's through alcohol and that the addiction that's probably caused it. They've never been abrupt or anything like that with them. [Substance use professional - interviewee]

6.2.2 Working with mental health and social care services

Both mental health services and social care featured in several of the discussions in both individual interviews and focus groups, although possibly not as much as might be anticipated given the complex array of needs many people's experience. However, difficulties accessing both services were noted by both substance use and hospice professionals.

One substance use specialist referred to the perennial dilemma of whether mental health services would offer support while a person was still using substances and how this varied across areas. Also mentioned was the fact that frequently people with substance problems did not meet the very strict eligibility criteria operated by mental health services and how this meant substance use services were left to support the person alone.

One of the hospice interviewees also described difficulties in engaging, or retaining, MH services in the context of people with EOL needs:

...we do try to work collaboratively if we can with both their, if they have already got a mental health team involved, to try to work collaboratively with them, but we do struggle because when they're under our care, they've got a physical health issue, often mental health feel that the physical health issue trumps the mental health issue, so often they'll want to take a step back and say that any issues that are going on, are more likely due to their physical health problems ... [Hospice professional - interviewee]

It is important to mention however, that these comments relate to formal mental health services; some mental health focused projects that had offered a service to people were also mentioned by participants.

Again, there were relatively few references to social care but similar issues arose with trying to engage social care. One interviewee described it as a 'fight' to access home visits; another relayed a story of someone who lived in a totally inappropriate residential care setting because an appropriate resource simply wasn't available. A third summed their experience this way:

I think social care is in a mess anyway, we all know it's in a mess so our clients that will be discharged from hospital, while workers in the hospital do their level best to put those supports [in place], there isn't the support in the community for social care. [Substance use professional - focus group]

Another team had mixed experiences of working with social care while occupational therapists (OTs) were more highly rated:

R: ...teams can respond really quickly if you get the right one. ...

R: I've always found OTs very good, social workers ... very varied.

R: Very patchy, yeah. [Substance use professional - focus group]

Indeed, throughout the narratives and story-telling of participants it seems that much of the 'social care' and possibly 'mental health' care ended up being provided by professionals from substance use services.

The challenges in terms of engaging other services in the care for individuals are then numerous and varied. There are perceptions that values and attitudes influence medical responses as do the time constraints on medical services and the way that people need to fit with the way services are delivered, rather than the other way around. Thresholds and eligibility criteria impact on the ease with which mental health and social care services can be engaged and the behaviours of people with problematic substance use can impact on the preparedness of other services to work with them. Nevertheless, sheer doggedness and persistence on the part of front line professionals, and their preparedness to sometimes go beyond the remit of their own roles allowed for a service to be delivered:

Sometimes it can be quite difficult because again, probably because of the other medical professionals are really tight on time and have got huge amounts of people to be dealing with, but the conversations that we have had with people and the time that we have spent, like linking things up and liaising with these professionals have really, really good communication for that person at that time, so I can't say forever, Dr So & So is always going to be brilliant but you could have had a good 20/30 minute conversation about someone which has been really profitable, so I think those links are there and they can be formed and I think everyone is willing, all the different partners are willing and wanting this kind of sense of joined up working but again, I think a lot of it is prevented by the time constraints on people. [Substance use professional - interviewee]

6.3 Section summary

Participants described major challenges for people with experience of both issues that largely related to: (1) other professionals' attitudes towards people with substance use difficulties, and (2) the inability of many people in this group to successfully engage with routine health services. Particular difficulties were identified in relation to some medical practitioners overlooking a person's health difficulties if they had been labelled as 'a substance user.' While it was recognised that both time and systemic constraints impacted upon medical responses for the whole population, for people with substance problems this was compounded by the fact that they struggled to 'fit with' the way that healthcare services are delivered. As with many areas, of social policy, there exists a significant gap in multi-agency responses for this client group, with services working in silos and difficulties engaging other services; access to both mental health and social care services in particular was highlighted in this context. However, amongst the identified service deficits, it is important to recognise the many frontline substance use practitioners who remained dogged and prepared to go beyond the remit of their own roles to care for people with substance problems.

Chapter 7. Asking or talking about the ‘other’ issue

In terms of the qualitative data, one of the *a priori* themes in the template analysis for both focus groups and individual interviews was ‘talking or asking about the ‘other’ issue’. This was retained following full coding and analysis. The interview and focus group data were independently coded initially and then combined due to the considerable overlap between the findings from the two data sources (n=17). The combined 122 coded extracts were clustered into four final themes and are presented in turn below (see figure 7.1 below):



Figure 7.1 Thematic clusters within ‘asking or talking about the ‘other’ issue

7.1 Current practice and views on asking

Participants mentioned the importance of asking about the ‘other’ issue for a range of reasons. These are listed below:

- Lengthening the life the person has left
- Improving the quality of life the person has left
- Accurate pain relief for people using substances
- Ensuring the care provided accounts for all the person’s needs
- Improving professional practice and care.

However, the variation in current practice demonstrated a lack of a consistent approach to asking about the ‘other’ issue. Only 14% (n=10) of hospice survey respondents and 10% (n=4) of substance use respondents reported talking often or very often with service users about substance use or health problems. There was little evidence of any routine or standard questioning in the practice of these professionals:

...we wouldn't ask it as a standard question, "Do you have any history of drug or alcohol use?" Maybe we should, but that's currently not what we do.

[Hospice professional - interviewee]

One exception was a small group of substance use professionals who had worked in specialist projects with older people or with people with particular health conditions that were life limiting. These project staff more routinely and confidently asked about life limiting illness and worked closely with GPs and other health professionals. Another substance use professional accepted that asking about end of life care planning might be something they would have to do if it had not been discussed previously with the person by the end of life specialists. However, they had the expectation that the person's treatment team would have been responsible for having such conversations.

Some hospice professionals stated that the referral information and process would normally pick up substance use issues and therefore it would be unusual for them to ask again. However, this experience of what would 'normally' happen differed between services within the same organisation. According to one hospice interviewee, a discussion among staff had resulted in a split of opinion as to whether questions should be asked about substance use or not:

There was a bit, it was a bit half and half, some were saying, "Well, because of the medication, that they may be prescribed, we have to know." And then others were saying, "Well, actually irrelevant of the medication, it's prescribed, they're individuals and I think that's something obtrusive going into their lives." So there has been...it depends on the individual's personality as well, yeah.

[Hospice professional - interviewee]

This theme of personality or personal experience determining people's willingness to engage with the 'other' issue was reflected in substance use agencies too:

I think that it probably depends as much on staff's personal experiences and either life experience and age or things that have happened to them, or previous jobs, I'm not so sure that it's our intentional preparation that supports them and how they use supervision and so on.

[Substance use professional - interviewee]

Discussion among hospice staff included experience of medical professionals asking questions about substance use and, in this instance, to conversation with the person's GP who asked the professional how they knew about the person's substance use:

..."I asked the question." He [GP] said, "Oh, I've known him for 30 years and never thought to ask him"... I got his [the patient's] consent to do that and I think it opened the GP's eyes and I said, "We need to have more discussions with patients about these issues and problems and that will help our prescribing for the future." [Hospice professional - focus group]

A common thread in relation to current practice around asking about substance use or end of life care, however, was the one of professionals' confidence, "... I think, it is more about how do you bring round the conversation to say that to people? [Hospice professional - interviewee]. Similarly, in one focus group, the substance use professional identified a lack of training as the reason for not being the "best person" to be saying "Well come on, you're getting near the end of your life, what plans have you got in place?" [Substance use professional, focus group].

There were differences within teams about people's willingness to ask questions which suggests some professionals were more willing than others to talk about the 'other' issue:

Participant 1 (P1): I've been quite lucky, I think I just haven't been exposed.

Participant 2 (P2): But do you ask the question?

P1: I don't because I've never had any reason to, I've always felt that unless I suspect something then I would ask the question.

P2: But if it was in an assessment and we did ask the questions, you might find more ...?

P1: I might do.

P2: I always say what goes on behind closed doors ...

[Hospice professional - focus group]

Of particular note is the participant's comment about being "lucky" not to have been "exposed" to people using substances in the course of their work. This suggests there may be attitudinal barriers to working with people using substances. Substance use was also identified as a taboo subject in one hospice which, in turn, prevented professionals asking questions about it.

A different perspective from one hospice professional said knowing about substance use could be detrimental to the care they deliver:

Sometimes I think, in some ways I'm quite comfortable about if we don't know about a patient's history of drug misuse because it's almost like the drug misuse becomes the driver for our decision making around symptom management, where actually we should be looking at the symptoms first.
[Hospice professional - interviewee]

7.2 When to ask

The timing of questions and the context for asking was discussed frequently. A number of professionals felt that establishing the relationship with the person first was important and that asking about the 'other' issue would happen but not until their relationship was established and certainly not on the first assessment.

It was not uncommon to find that participants waited for a trigger of some kind to ask about the 'other' issue. For some, the presence of clinical indicators or other health-related information prompted them to investigate further:

I'll give an example of a patient that I went to see recently who was having difficulty with symptom control issues with pain, and painkillers were being escalated rapidly for this gentleman, without any significant benefit, and I posed the question to him, had he ever had issues in his life with using any drugs or alcohol excessively and he then discussed openly with me, what in the past he had used and done. [Hospice professional - focus group]

One person said it was professional "instinct" that prompted further exploration but reflected that this could miss people who were using substances. For others, they waited until the person raised the issue themselves. For some professionals the timing of when to ask related to their perception of whether or not it was appropriate in a situation where someone was near the end of their life:

...we're used to asking difficult questions about issues, and it's not that the alcohol question or drug use question was difficult. It just wasn't appropriate. And that's different. [Hospice professional - focus group]

The fact that substance use was the least of the person's worries once they were in the hospice was mentioned by a number of professionals in the course of the research. One hospice professional stated they suspected more people than they knew had alcohol problems but they didn't "ask too many questions".

In a similar vein, the substance use professionals pointed out that not everyone will be ready to have a conversation about end of life care nor will it be their priority:

... you might have an inkling from how someone is presenting but some people are hugely in denial about the fact that their alcohol use has caused them any health issues, and it really doesn't matter what you say, they're not going to take that any further, they're terrified of the GP, they're scared of the hospital, so it can be quite difficult in those sort of situations because it's like you've got alarm bells going off. But if somebody is just not in that place to listen, it's kind of learning and knowing when to ask those, sort of, more probing questions and then where to take that ... [Substance use professional – interviewee]

One substance use professional highlighted the importance of not leaving it too late to try to have a conversation with people about end of life planning although accepted a challenge was to get other professionals "thinking and acting like that".

7.3 How and what to ask

The discussion with the professionals sought to establish what type of questions they were asking about a person's substance use or life limiting conditions and how they were doing so. Among substance use staff, some described their comprehensive assessment process as including questions on physical and mental health issues but nothing specific which supported any enquiry into end of life care planning.

Some participants talked about people being more open to discussing their substance use once they had started the conversation about it and when the person knew they were not going to “run to the police” [Hospice professional - focus group]. Another felt that a blanket statement might work better:

...we're at fault for not asking those questions and maybe we should do it as a blanket statement like we ask: “What’s your pain like?” “Have you ever had a problem with drugs? Have you ever had a problem with alcohol?” And it’s not about being judgemental, it’s about empowering us to give them the appropriate treatment they need. [Hospice professional - focus group]

The language used and how people asked about the ‘other’ issue varied according to context with one hospice professional recounting how openly she could ask about substance use within a community setting. One substance use professional did not like using particular words: “I don’t like saying the dead word or whatever” [Substance use professional - focus group]. Substance use staff were critical of medical staff whose choice of language sought to scare people into changing their behaviour and were clear that it didn’t work: “I think doctors feel they’ll frighten people into changing. Often it makes them drink far worse.” [Substance use professional - focus group]

One participant recalled one of the people they worked with who had died and how, subsequently, they wished that they’d had the conversation with them. Some participants also offered examples of how this could be done sensitively:

... you can always use the word with a client and it’s a big word, the “if” word, “If things were to go that way, what are your thoughts on it? What would you want to happen?” but don't forget it’s an “If”, it’s like asking the hypothetical question... [Substance use professional - focus group]

Another thought that someone’s hospitalisation could offer an opportunity to develop a conversation about planning for end of life, a brief intervention, asking a series of questions about their wishes:

I said for me, what I want is a brief intervention that our staff can do in the spirit of palliative care that means that we can use an opportunity like: “Cor blimey, Tony, you're in hospital, it was really a close call wasn’t it? I didn’t know whether you were going to come out or not.” You know? “And it made me realise there was things we hadn’t talked about and I think maybe we should, maybe we should have a thought about if you weren’t going to come out, who did I need to contact? What would you have wanted to happen? Who would you have wanted to be involved?” ... It’s using that opportunity better. [Substance use professional - interviewee]

7.4 Concerns about asking

It was clear that some professionals had concerns about asking questions about the 'other' issue. Among the reasons were a lack of expertise, not knowing what to do with the response, and feeling uncomfortable about asking:

...if nobody else is going to bring it up, then I suppose we need to bring it up. But it's a bit like Pandora's Box, if you start it, and then you don't know how to address it, ... or direct it then you can't open that box, because you're going to create so many more problems for that person.
[Substance use professional - focus group]

Others felt that questions shouldn't be asked unless something was going to be done with the responses:

What are you asking them for? Do you drink 100,000 units a week?
Yeah. Okay [laughter]. I'll just write that down. You're not going to do anything with it.
[Hospice professional - focus group]

They also identified the need to have someone around them who could answer any questions they might have. One hospice-based professional group pointed out that in order to ask the questions, they needed someone to ask if they didn't know the answer. Substance use professionals agreed that their confidence had increased as a result of regular meetings with a local "end of life consultant" [Substance use professional - interviewee].

Concerns about 'upskilling' new staff to ask questions as part of the assessment process was identified as helping them to overcome a fear of asking or to overcome stereotypical views of people with substance problems.

7.5 Summary

This chapter has explored challenges identified by professionals of asking about the 'other' issue. While being able to ask was identified as important for a number of reasons including improving quality of life and adequate clinical oversight of their care, there was little evidence of routine questioning in the current practice of either hospice or substance use professionals. In both groups participants varied in their willingness to broach the subject, indeed in one hospice focus group a participant suggested talking about alcohol or drugs was 'taboo'. Both professional groups thought it was important to have built a relationship with the person before asking questions about the 'other' issue and, where conversations did happen, they would occur naturally at a time and in a context that felt appropriate to the professional. Discussions about how and what to ask again revealed variation, particularly within the hospice group, with some participants feeling that routinely asking about substance use, in a non-judgemental way, would be helpful in managing care although there was also the suggestion that treatment should simply be symptom led and there was no need to intrude into people's lives. Personality and the personal experiences of professionals were thought to play some part in how willing they were to engage in

conversation about the 'other' issue. Substance use professionals identified a concern about using language which was too associated with death but suggestions were made as to how conversations about end of life planning could be introduced sensitively. Finally, the analysis revealed a range of concerns about raising the 'other' issue: first; there were worries about not knowing how to follow up; second, that questions should only be asked if you were going to do something with the information obtained; third, it was important that there was someone available for professionals to consult with on how they dealt with these conversations.

Chapter 8. Managing medications and prescribing practice

One of the earliest messages we heard in this research about substance use and end of life or palliative care related to the challenges it poses for symptom and pain management. It is a dominant theme in a number of the strands of this programme of research including the Rapid Evidence Assessment of the existing research (Witham et al. 2018), the key informant interviews (Templeton et al. 2018), and the interviews with family members of people receiving end of life care (Yarwood et al. 2018).

For the professionals strand it was a key talking point in the focus group data and, to a lesser extent, in the individual interviews. Once again, the data from both strands of data collection were merged resulting in eight sources and 76 coded extracts. These were further clustered thematically into three categories and one sub group (see figure 8.1 below):

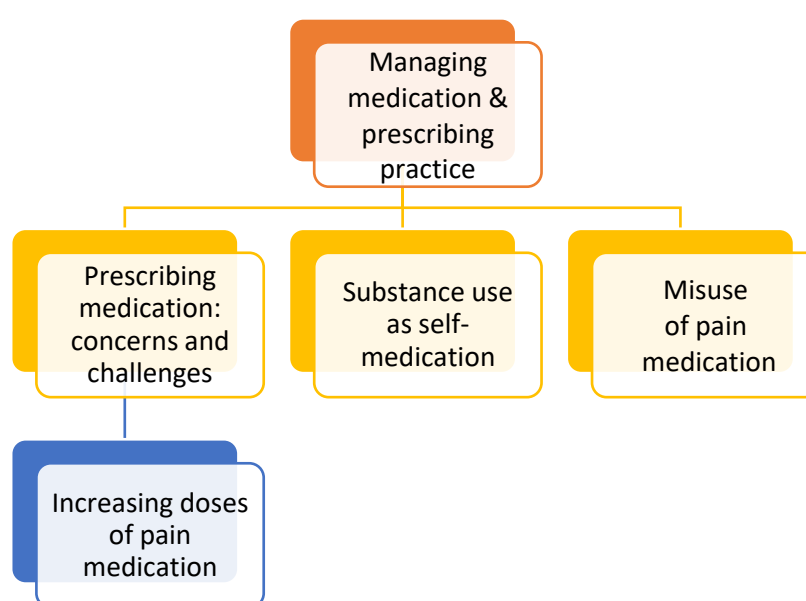


Figure 8.1 – Key thematic categories relating to Symptom and Pain Management

Unsurprisingly, much of the data on this topic came from the hospice professionals but there were some limited data from the substance use professionals too.

8.1 Prescribing medication: concerns and challenges

One of the key concerns about prescribing medication was the possibility of poly-prescribing and poly-pharmacy. Professionals spoke of wanting to keep track of which professional is prescribing which drugs to people, and how the various prescription drugs interact with each other and with other substances [Hospice professional - focus group]. The hospice professionals communicated with the GP about prescribed medication but were aware that there may be others involved in the person's health care:

We let the GP know but if that patient's known to an oncologist or a heart specialist or a renal specialist and they also have community matron and they have a GP, you've potentially got four or five people who can prescribe. [Hospice professional - focus group]

This group of professionals also raised the issue of people with substance problems “bouncing in and out” of services adding to the difficulties keeping track of prescription medication. Some concerns related less to keeping track of the prescription medication but rather a concern about GPs in particular, being reluctant to, or afraid of, prescribing end of life drugs to people with problematic substance use:

I think sometimes I've had an issue where GPs... have been reluctant to put end of life anticipatory medications in if they know there's been a history or there's some people in the family that have got problems with drug use.

[Hospice professional - interviewee]

I think, generally speaking, there's a huge ignorance in managing pain in patients who are either current drug users or past drug users at end of life with cancer. There is a fear isn't there about prescribing? [Hospice professional - focus group]

Another concern was people around the individual, such as family or friends, stealing and/or using the medication leading to the hospice at home staff needing to check and count the drugs each day although the hospice staff we spoke to had very little knowledge of that happening but it was a precautionary measure:

...we've had it where CDs [controlled drugs], end of life drugs have gone missing in houses, so then we've had to have locked boxes. [Hospice professional - focus group]

Quite frankly they've got bottles of morphine on the side of their bed anyway where their friends can ... and we do know that that's happened, that their friends have been helping themselves. [Hospice professional - focus group]

There is some drug misuse, but that's occasionally been family members... Yeah it would have been highlighted, wouldn't it, probably from another service that actually there was a drug user or in the family, and there would be an alert that we'd have to be more careful. [Hospice professional - focus group]

8.2 Increasing doses of pain medication

Professionals talked frequently about how people with substance problems required more or different medication combinations in order to address their pain or symptoms adequately. This is because their substance use had created a physical tolerance to some prescribed drugs, particularly opioid drugs that would normally work well for people.

... I know that I struggled with thinking about the drugs and what to suggest prescribing. I mean if somebody's on so much Diazepam that they're taking, you know, what do you then do in terms of symptom management? How do you manage their anxiety when they're already taking shed loads of Diazepam? [Hospice professional - interviewee]

One group gave an example of a person who had a history of "heavy substance use" and having to give high doses of medication "to knock him out like a horse" due to his high tolerance levels [Hospice professional - focus group].

The issue of increasing pain medication doses left some professionals feeling reluctant or fearful of potentially overprescribing. Nurses and GPs were concerned about giving 'Just in case' medication to people with substance use histories. The higher doses of prescribed medication were also an issue for nurses coming from community to hospice as they saw huge increases in the pain medication prescribed. Pharmacists who dispensed the medication were reportedly worried about high doses too:

Because you know, if you're the one that's administered it, you're responsible. [Hospice professional - focus group]

One professional pointed out that escalation of pain relief suggested questions needed to be asked about their substance use and history. In asking the question one professional stated that the person spoke openly about it and the professionals were therefore able to change their medical management of him [Hospice professional - focus group]. There were also reports that the same approach was applied to alcohol dependent people in that medicines could be adjusted in order to support people as best as possible.

However, examples were given of GPs who needed the professional to advocate for the person in order to get around the GPs fears of prescribing. One woman required increasing measures of morphine to control her pain but her GP was reluctant to give it despite her having been "clean for 12 years" [Hospice professional - focus group]. Other people found difficulties getting the prescribed medication they'd received in prison settings, when they returned to the community, as the community GP would not prescribe the same medication before trying the person on other drugs. [Hospice professional - focus group]

There were examples of good practice too. One focus group stated they had a GP who knew what methadone levels the person with cancer was on so gave him "the appropriate dose of morphine." Another said that their palliative care consultant had to go to hospital because of the hospital's "prejudice" to explain the person needed a higher dose. They also invited the district nurses to the hospice to talk about prescriptions for this group of people "because if we just sent [the prescription] out, they would have fallen over when they saw that [quantity]" [Hospice professional - focus group]. As these staff pointed out, such information and advocacy "helps to treat the patients when they get back in the community."

8.3 Substance use as self-medication

Throughout the data collection, substance use as a form of coping was raised, whether that was coping with physical pain relating to their illness or to psychological or emotional pain. Cannabis in resin or oil form was often cited as a substance that people saw as helping with symptoms. One group commented that for some people it was seen as a treatment need rather than an escape [Hospice professional - focus group].

Eventually we build up that relationship with them they'll say, "I'm taking cannabis oil. They're quite ashamed of it at first, because they associate cannabis with drug users and they're actually taking it because they've heard something it can cure cancer and it can do all these things.
[Hospice professional - focus group]

Myself and another colleague brought [a patient] in ... his son had gone and got some under the counter medication for him. ... It was cannabis oil and what he'd done is actually because he thought that this also would make his dad better, because the chemo hadn't worked. In his mind, he'd been told that this was a cure ... His dad, he stopped all his medication and we kept upping his medication. ... He died in here, but [the son] still couldn't get his head round this, because he'd been told that this was a cure and he was absolutely fixated on it, thinking he was saving his daddy. But he'd not been taking his morphine probably for two weeks. He was in agony ... [Hospice professional - focus group]

Professionals also reported alcohol being used "because this is my painkiller" [Hospice professional - focus group]. There was one instance, however, of alcohol being used as a medication to calm an agitated person with severe cognitive impairment who was not willing to take prescribed medication. It was a possibility that the person was experiencing withdrawal from alcohol and was unable to communicate it verbally.

Professionals also cited a number of herbs and spices being used as a substitute for other drugs, including Cumin, Turmeric and also mushrooms. The concern about such substances was the interaction with the prescribed medication and the mix of drugs adding a layer of complexity to the person's care. Some hospice staff were very aware when the person had gone out of the hospice to take a substance and then returned a little while later. One person referred to this as "... self-medicating somewhere up the road" [Hospice professional - focus group].

In addition to the use of substances to assuage physical pain, some professionals noted people wanting the medication for emotional relief rather than physical pain relief:

... we do have patients who sometimes say, "Can I have my pain injection?" and they don't appear to be in pain but that's not just people [laughs] people do use it as a way of having a bit of a sleep but again, that's what people see, they recognise that patients sometimes will ask for something just because the emotional suffering of what's going on for them is unbearable and actually just having a painkiller to just have a bit of a doze is more acceptable.
[Hospice professional - interviewee].

8.5 Misuse of pain medication

The professionals provided a number of examples of people who had misused prescribed pain medication including:

- One person who had buried medication in the grounds of the hospice for use when he went into the gardens [Hospice professional - focus group].
- People who sought prescriptions for opiate-based medication from multiple sources including the oncologist, GP, and hospital [Hospice professional - focus group].
- The misuse of pain patches including smoking them, "dissolving" them and "sharing them out" [Hospice professional - focus group].
- Selling on some of their pain medications, "not just opioids but things like diazepam, lorazepam" [Hospice professional - focus group].
- Use and misuse of pain medication by family members or friends (see chapter 9).

One group highlighted how if a person asked for a particular drug, it would trigger concerns and questions about what they were wanting it for [Hospice professional - focus group].

A number of professionals offered solutions they had found. Two hospice groups had introduced a system of agreeing who would prescribe the medication – be that the GP, psychiatrist, consultant – essentially one professional only [Hospice interviewee; Hospice focus group]. Another said that good communication between professionals was important [Hospice professional - focus group], as was communication with the individual themselves:

... so you've got, sometimes, I suppose it's communication and bridging a gap really and trying to explain [Hospice professional - focus group].

Just by being very explicit with people and saying, "This is what this is for and again we expect you to use it in this way, account for every vial of it", we haven't had any vials lost or not accounted for. [Hospice professional - interviewee]

Not all participants were as invested in accounting for all medication. Where morphine-based medication is prescribed in order to maximise a person's pain relief when very near death, one professional said "nobody's going to count them tablets at the end of life are they because [the person is] dying anyway!". [Hospice professional - focus group]

In the case of the person burying drugs in the garden of the hospice, staff challenged him, not on the grounds of his substance use *per se*, but on the grounds that the effects of the prescribed drugs would be unknown:

...we basically said, "We'll discharge you if you keep doing it because we can't do this, we can't have you taking these drugs whilst we're giving you these because we have no idea what the effect is going to be on you, so you need to work with us." And in the end it was resolved as far as we know, it stopped"

[Hospice professional - focus group]

However, there were also instances where people with histories of problematic substance use refused opiate-based medication even at the end of their lives:

I've come across the opposite, where people with a drug problem in the past are so reluctant to consider painkillers again because they're so fearful, ...

[Hospice professional - focus group].

I do have another lady on my caseload just now, who is an ex user. And interestingly, she really will not take it. She won't take the liquid morphine, she's terrified of taking it. She'll try and put up with the pain, because of that fear of addiction. ...There is a fear if they've been clean for a while, there really is a fear of getting back on and that. It's like they feel they're going to lose total control of their lives. [Hospice professional - focus group]

8.6 Summary

Symptom and pain management for people with a history of substance use has been a key theme across all the strands of this programme of research. This chapter has examined concerns and challenges in relation to prescribing medication, substance use as self-medication and misuse of medication prescribed to relieve pain.

A particular challenge was identified in relation to the number of clinicians who might be involved in prescribing for people who have multiple co-morbidities and the need to avoid the risk of unhelpful interactions between prescribed drugs and/or other substances. Also clear from the data was a perception among hospice professionals that GPs are often reluctant to prescribe end of life medications where there has been a history of substance use. There were also worries about the safety of end of life medication stored in people's homes, where they might be used wrongly or used by others.

Hospice professionals noted that it was often necessary to provide medications at dosage levels that were significantly higher than normal because of increased tolerance levels and that these high doses could raise anxieties for other health care professionals such as the pharmacists responsible for preparing the prescriptions or the district nurses responsible for administering them. The use of alcohol or cannabis (or other substances such as Cumin, Turmeric or mushrooms) as 'self-medication' (for either physical or emotional relief) was

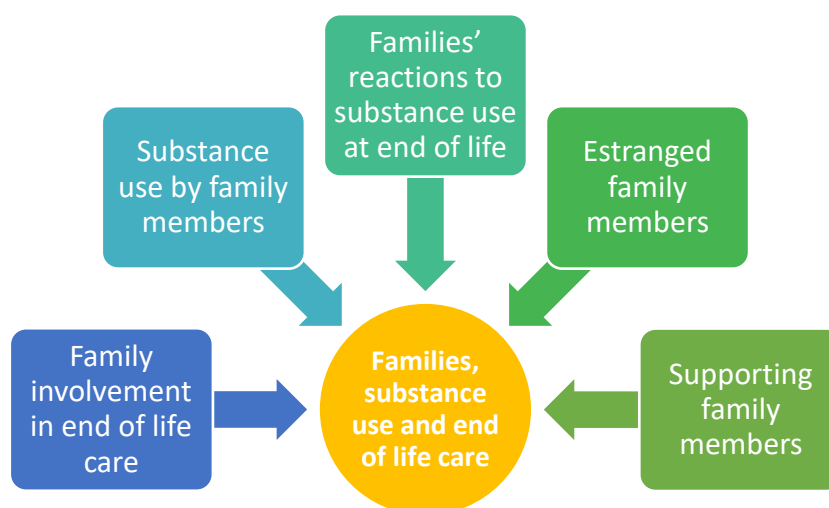
highlighted as complicating care management, again because of the problem of potential interactions. A number of examples were given of people who misused prescribed medication, including seeking prescriptions from multiple sources or selling on drugs prescribed to them, which refers back to the need for clarity on who within a person's medical team is prescribing what and when. On a final note, some professionals also identified that some people whose substance use was in the long distant past may be reluctant to take opioids, fearing renewed addiction.

Chapter 9. Families, substance use and end of life care

Another strand to this programme of research explored the experiences of family members, friends and carers (hereafter, 'family') of people with problematic substance use and end of life care needs (Wright et al., 2018; Yarwood et al. 2018). However, we were also interested in the experiences of the professionals in relation to family support and family involvement in people's end of life care and substance use.

Themes were drawn from 149 coded extracts from 15 sources. As illustrated in figure 9.1, the main themes concerning families related to family involvement in end of life care, families' reaction to substance use at the end of life, problems associated with estrangement, supporting family and friends, and difficulties associated with substance use by family or friends.

Figure 9.1 – Sub-themes related to the theme of family and friends from professionals' perspectives



Most of these aspects featured in both interviews and focus groups and were discussed by participants from both substance use and hospice services.

9.1 Family involvement in end of life care

While family involvement in end of life care is often conceptualised as a supportive family caring for a dying relative, the survey found that 57% of hospice staff reported that they had worked with people where there were concerns about a relative or friend having a substance use problem. Thus, family involvement can be both positive and negative. The survey also found that 37% of substance use staff had worked with people who had family members with life-limiting conditions.

Family issues were discussed in both focus groups and individual interviews, although more so in the former. The following quote from a hospice professional taking part in one of the focus groups brings to life the issue when these needs overlap:

... if somebody said to me “I’ve got a drink problem, I’ve drank for years but it’s wrecked my family”, I wouldn’t be thinking about LFT and liver functions. I would be thinking where’s the family? How messed up is this person? What can you put in place before those six to eight weeks runs out and they’ve died, and we haven’t provided any help, ... [Hospice professional - focus group]

Professionals perceived family involvement in supporting their relative as both positive and negative. Hospice staff discussed the importance of families being able to share with professionals their perceptions of their relative’s experience and to challenge their relative to be open about their pain and discomfort. Examples were provided by both hospice and substance use professionals of situations in which the family helpfully shed light on the relative’s physical and mental health because the relative was not being completely open or truthful.

...having regular contact with the family members... because you’re going to have clients that obviously sit down and go, “Yeah, yeah I’m fine, I’m fine, yeah, nothing wrong with me, I’m fine” and then when you talk to the family members they’ll say, “Well, actually they had a really bad week last week” and they was really down, and then you can talk to them again the next time you see them. [Substance use professional - interviewee]

However, there was also complexity in working with family members. One substance use focus group recalled a number of situations where they got caught up in difficult situations between family members, either when the family was arguing or when the relationship was erratic and consent for contact was given then withdrawn, then given again:

I mean I had a guy who was wanting contact with his daughter so he gave consent for me to speak to the ex-partner ... then when he went off the rails he withdrew that consent. ... Now he’s back on the rails again he’s like, “So, can you speak to [ex-partner] again?” [Substance use professional - focus group]

9.2 Families reactions to substance use at the end of life

Hospice staff discussed the importance of families being able to share with professionals their perceptions of their relative’s experience and to challenge their relative to be open about their pain and discomfort. Examples were provided by both hospice and substance use professionals of situations in which the family helpfully shed light on the relative’s physical and mental health because the relative was not being completely open or truthful. However, there was also complexity in working with family members with professionals often getting caught in the middle of changing family dynamics.

Professionals noted anger and frustration on the part of some family members that their loved ones would not, or could not, stop using substances. Family members were reported as wanting their relative to “fight” their illness and getting angry with their relative if they felt they had given up.

When you speak to those families, families themselves can get angry, because they feel that this person has done it to themselves. [Hospice professional - focus group]

Participants in one hospice focus group continued to discuss how difficult the bereavement process can be if relatives are angry before death and haven't taken the chance to try to put things right. One of the individual interviews also touched on this issue of how families respond when learning of their relative's substance related ill-health. In particular, one interviewee highlighted how families can respond in markedly different ways ranging from being 'used to it' to families that 'push' people to getting better.

In contrast, both participant groups reported having observed some family members and friends supporting their loved one to continue to drink, alongside other relatives expressing anger at either their relative because of their continued use, or professionals for not stopping the person from drinking. Thus, while one hospice-based focus group reflected on a case where a daughter took a flask of whisky into the hospital for her mother, because "I knew my mum would enjoy it and I knew she was dying" [Hospice professional - focus group], Conversely, another focus group mentioned a situation where a person's daughter burst into tears when her father was offered a brandy and dry [ginger] in the hospice saying "My dad's not drank for 25 years," [Hospice professional - focus group]

Although not explicitly stated in the focus group discussions, it was noticeable that whenever supporting continued use was mentioned, this occurred alongside conversation about drinking among family and friends. Thus, it may be that the difference in attitudes expressed by family members is accounted for by whether or not the relatives are drinkers themselves. For example, among the cases discussed where relatives were supporting continued use, was a man whose condition was such that he could not walk and he needed weekly draining of ascites but was able to continue to drink because his wife supplied it [Hospice professional - focus group]. This participant went on to say that she suspected this man's wife was a drinker as well.

9.3 Substance use by family members

As discussed in chapter 8, from a hospice perspective, there were concerns about the safety of take home prescription medicines for people at the end of life when there were substance users in the home, or with access to the home. Professionals needed people to be open about the potential for medications to be stolen, so that appropriate measures could be put in place. Those safety measures might include the use of a safe or arrangements about there being only one prescriber. There was particular concern too about proper management of 'stock-piled' drugs that people no longer needed.

There was also a reflection in one of the focus groups that many nurses have disproportionate fears about risk and would get a safe installed even if a relative had used drugs many years previously and currently lived hundreds of miles away. Hospice staff also talked about the difficult ethical position they could find themselves in when working in homes where illicit substances were used and questioning what they could do and how far they could 'step in' and raise the issue with the family members concerned. Hospice staff

who worked in peoples' homes also mentioned the aggression they could face from family members who were using substances.

Participants raised additional concerns about the family members' use of substances when their relative's condition deteriorates and the person dies. In particular, they were concerned about substances being used as a coping mechanism by the family members.

Other potential risks to health care providers and other family members were also identified, for example, one participant related the story of a young intravenous drug user living with an elderly person, and neither were coping:

So, the police come, then an ambulance comes, and I've had to literally back out and do like an incident to Social Services for safeguarding. They came back, and actually he'd been putting dirty needles in his father's commode and one of the ambulance men that were moving him nearly got a needle stick [injury].

[Hospice professional - focus group]

Relatives visiting hospices in an intoxicated state could also be challenging for staff. In one focus group, participants described relatives needing to be put into a taxi to make their way home. In another situation, the daughter of an in-patient was staying in the hospice and was clearly using substances which left the night staff feeling vulnerable because of limited staff cover.

A final difficulty for professionals was when the family environment was promoting substance use in spite of their relative's attempts to change their substance using behaviour:

We worked with him, not for very long because he was just surrounded by it, I think his mum and dad and uncle and everybody else smoked cannabis. It was very difficult. [Substance use professional - interviewee]

9.4 Estranged family members

It was noted in both focus groups and some of the interviews that people who had substance use problems were often isolated from family and may be more likely to die alone:

Often people will die alone due to the nature of their addiction, families have sort of, they've alienated themselves from families and support networks and stuff like that, and often we're probably the only support available to them.

[Substance use professional - focus group]

In relation to the professionals' role when families were estranged, participants made the point that it was important to think about each case individually in relation to working towards re-unification, and that it was something that would need to happen naturally.

Another participant gave an example of a woman she had been working with who had several children living in various parts of the country. Two of the children, when traced and told about their mother's condition, were reported to have said they were "not interested" [Substance use professional - focus group]. These cases highlight the precarious nature of trying to re-establish contact in these circumstances. In another case, the relative was reported to have agreed to offer some support – but "at a distance":

I phoned his brother and had a conversation with his brother and he said, "I've been dealing with this for over 20 years, I'm tired, I've had enough. Yes I'll go and visit him at hospital and I will support with that but from a distance."

[Substance use professional - focus group]

The above observations and quotes are all from substance use professionals and all highlight difficulties with engaging with estranged families. However, it was also an issue discussed and addressed within hospices including attempts at reconciliation the result of which "can be really positive, but sometimes [not]" [Hospice professional - focus group]. One hospice professional highlighted her experience that it was usually the "ex-wife or ex-partner" that offered support near the end of the person's life.

In sum, the testimony from participants in this study suggest that reconciliation of substance users with their families at the end of life may not be easy.

9.5 Supporting families

For substance use services, the working relationship is very much between the individual and service (or worker) and considerations of confidentiality are paramount. Nevertheless, while an individual was alive, support could be offered to family members in their own right through carers groups or CRAFT groups ¹, which operated in the substance use agencies taking part in the study.

In one focus group there was discussion about the family group being open about the potential for their relative to die suddenly or to develop life limiting conditions:

We run a family group here and that is family affected by drugs, alcohol and gambling and that is something we talk about because we all accept, including myself, that there's every chance my son's going to die before me...

[Substance use professional - focus group]

The discussion went on to emphasise the importance of preparing for death, even though there is no way of knowing when that might happen and how helpful it was for the group to be able to call on the substance use agency to provide training as needed.

¹ Community Reinforcement and Family Training (CRAFT) teaches family and friends effective strategies for helping their loved one to change and for feeling better themselves.
<https://motivationandchange.com/outpatient-treatment/for-families/craft-overview/>

There was also quite a lot of discussion about support after bereavement. One of the substance use agencies that participated had experience of providing a bereavement group. It was felt that access to this group would have been much quicker than accessing a service such as CRUSE and, further, that the ability to bring together people bereaved specifically by substance use was likely to be less stigmatising for participants. To paraphrase the words of one participant, the bereavement group “helped families not feel alone”.

None of the hospices in our sample ran dedicated family support groups though they did offer individual counselling and they reported that families were involved in people’s care and often needed support or direction. Families were often trying to better manage people’s home environments. For example, end of life care was being managed at home for a man who was a poly drug user, believed to be using illicit drugs (presumably supplied by friends or acquaintances) alongside his prescribed medication:

It was also [about] speaking to the family and saying “Look, if you know who these people are, you need to speak to them and stop them from coming because this is not helping him and it doesn't help us”. [Hospice professional - focus group]

As one hospice group pointed out, ensuring that people and their loved ones found ways of beginning those difficult conversations (about terminal or life-limiting diagnoses) was important, and staff often acted as that bridge:

But when they go back, and you have that conversation with them on their own, then very much they'll say things what's bothering them. Eventually they'll say, “Well I'm really worried about my family,” and you get all that. Then we have the conversation, “Have you tried talking to them, because it's helpful?” “Oh, they will be too upset.” ...And that takes a few visits to break that prejudice down and then you go in the one time and they'll go, “We've had the chat, you made us cry.” It's good, so that happens a lot. [Hospice professional - focus group]

9.6 Summary

In summary, it is clear that family (or friends) have an important a role to play in supporting people with experience but often relationships have already been fractured to the extent that family members are reluctant to step in. Family involvement can also undermine professional support particularly where those relatives use substances themselves and pose risks to the safety and security of health personnel and prescribed medicines stored in the individual’s home. Professionals also expressed concerns about the well-being of relatives when a person with substance use problems died, particularly when those family members were using substances.

Chapter 10. System level challenges

Among the key discussions and debates at a systems level was how the topics of focus for this research were defined. For substance use staff one of the crucial challenges was identifying who they would categorise as end of life given the higher prevalence of sudden deaths among the people attending their services. The changeable patterns of substance use of their client group combined with an increasingly complex and fluctuating health status resulted in a lack of predictability regarding end of life:

...the cancer things are quite predictable, you can almost see where things are but with the organic deaths, it's this lumpy bumpy graph that you don't know where you are from one minute to the next... [Substance use professional - focus group]

Hospice professionals did not identify the same degree of challenge but were aware that they struggled to identify or ask about substance use causing some degree of concern for clinical matters like prescribing practice (see chapters 3 and 8).

Further, the system level challenges identified by both sets of staff highlighted a host of gaps and resource needs within both sectors and the challenges of policy in supporting or condoning these limitations. A total of 190 coded text extracts, across 17 sources (10 interviews and seven focus groups) clustered into two overarching themes and five sub-themes (see figure 10.1 below).

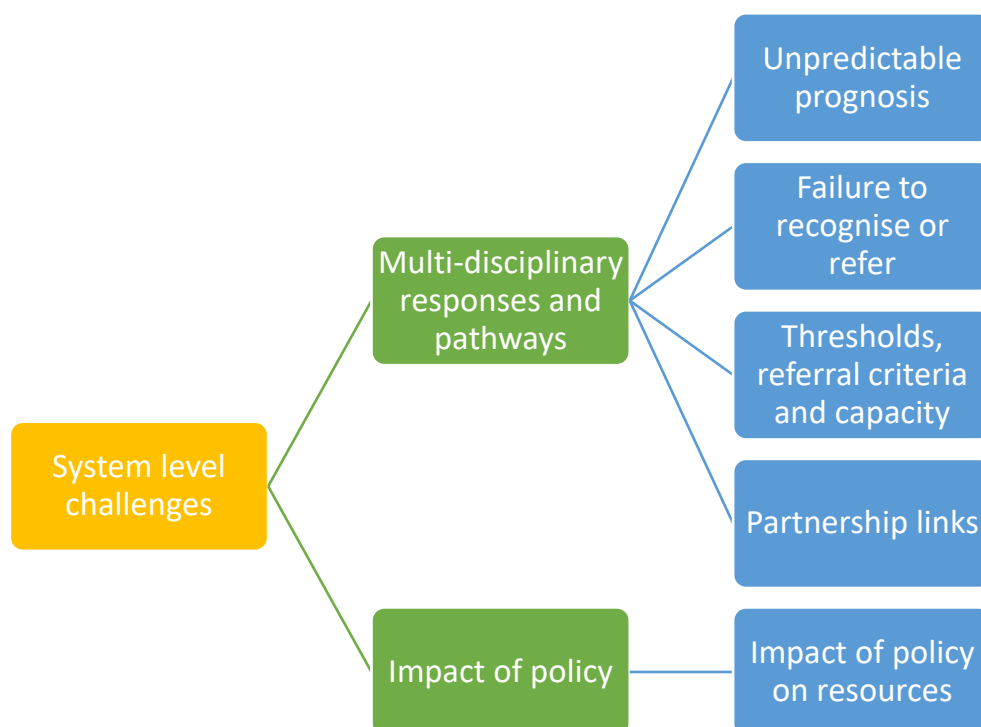


Figure 10.1: Themes and sub-themes within systems level challenges

10.1 Impact of policy

Different levels of policy were perceived to be unhelpful in supporting this group of people in three ways. First, on a national level, there were references to the current substance use policy focussing on 'recovery', rather than managing care. This had an impact on one practitioner's view of their practice model:

I think we should always be looking at not giving up on people and trying to affect some change, as I say, even if it's very, very small... , [Substance use professional - interviewee]

This can be seen to be particularly problematic when people are nearing end of life and has the potential to present tensions between substance use and end of life services. However, views differed with one focus group discussion highlighting a perceived move in the service to a different mindset of managing long-term conditions:

... there is a big acknowledgement at the moment, in particular with the opiate clients that we have, of just becoming managing long term conditions and taking the recovery - and the need to remove the substance misuse and the prescription medication that we're given - and swapping that just for a management plan. So that's a bit of a switch because previously we hadn't had that. [Substance use professional - focus group]

Second, at an organisational level, policy also had an impact in relation to the Serious Untoward Incident (SUI) procedure, which set processes in train if a person died while in their service. Substance use professionals were critical of these procedures in relation to the way in which they were held personally accountable:

... As soon as we get that person and their name goes on our caseload, from that moment we are held responsible and accountable for every single person. So, as soon as you've got a death on your caseload we end up having to go to these SUI meetings at head office ... and you're pretty much grilled, aren't you, really? [Substance use professional - focus group]

There was concern that these processes were perceived to focus on their management of cases, and were seen as a failure of treatment, rather than focusing on whether a person was well supported in their time with the service prior to their death: that dying with dignity was not 'measured', not considered a positive outcome.

A third policy concern at national and local levels was highlighted by one substance use interviewee who drew attention to how end of life needs did not feature in any of the substance use policies:

I've not seen much in the public domain, say for instance in some of the research publications or in any of the drug wise or national agenda, doesn't seem to crop up much unless... I've not seen it in the drug strategy. I haven't seen it referred to in the drug treatment guidelines in any shape or form, unless I've not read them properly. [Substance use professional - interviewee]

Some substance use professionals identified this as resulting from political decisions about the location of alcohol and drug policy:

That's a political decision that tries to put alcohol and drugs in the, well it's now in the criminal justice agenda and actually in the [United] States [of America], addiction is part of the main mental health service, it's all integrated over there and ours is side-lined very neatly – and the budgets – which are reducing all the time. [Substance use professional - focus group]

Finally, substance use staff highlighted that the palliative care and end of life “charters” had not been realised:

I think that [the] palliative care movement is obviously under pressure, Hospices UK and National Council for Palliative Care have just merged to merge costs because they're under pressure, everybody's got great charters about palliative care and improving things in their NHS trusts but they're not really translating incredibly well. [Substance use professional - focus group]

10.1.1 Impact of policy on resources

Chief among the gaps identified was the pressure services were under given funding cuts, lack of resources, and being unable to meet demand for services, or deliver services the way they should be delivered. However, direct reference to resources was, again, only apparent in the narratives of substance use professionals.

Specific to this study however, substance use professionals identified the impact of recent funding cuts resulting in loss of staff which meant lack of time to spend with people and an inability to offer proper outreach work. Loss of staff had also meant loss of some particular roles within organisations and loss of expertise.

...we're losing quite a lot of professionals ...[and] we're losing a lot of knowledge and expertise and experience because of the pressures that are coming through with that sort of very tight, short tendering cycle and the money that's being taken out of services as well. [Substance use professional - interviewee]

... funding is dropping all the time, you know, they want more for the money that they're paying out. [Substance use professional - focus group]

Concerns about funding issues could also be detected in relation to commissioning of services where staff were concerned about the sudden cessation of projects, or the fact that there was no space in increasingly squeezed teams to do the type of joint working they wanted to do, and the impact that this had on service users. Hospice professionals recognised this squeeze on substance use services and budgets:

I do think the big issue is that drug and alcohol services are overstretched, under-resourced, in a time when I think the complexity of the patients that they need to manage, and the number of them because the prevalence is increasing, means that their ability to engage with us is undermined because they just haven't got the capacity to do it. [Hospice professional - interviewee]

While hospice services had not yet faced the same severe cuts in budget that substance use services had, they had also not seen any increase, in spite of rising costs and the rapidly ageing demographic suggesting a greater need for more end of life services:

... certainly our block contract that we get hasn't increased, so you know, the price of inflation and bills going up, that hasn't been reflected in what we get, so our percentage that we've had each year has dropped, although the amount of money stayed the same. [Hospice professional - interviewee]

10.2 Multi-disciplinary responses and pathways

As outlined in chapter 6, a series of challenges or barriers to working effectively with other services in individual cases were identified. Some of the themes identified in participants' narratives took in a wider perspective however, raising questions about systemic or structural issues which caused problems or identifying areas in which links might need to be developed at a service level rather than the level of the individual person in services. There was considerable talk of services working in silos and a lack of appropriate referral pathways, particularly in the individual interviews. The four sub-themes under this second level theme of multi-disciplinary response and pathways are summarised below.

10.2.1 Unpredictable prognosis

One fundamental issue which has been discussed elsewhere in this report was the fact that the impact of substance use related harm can be uncertain. This, in turn, can be seen to be associated with how other services, particularly medical services, respond in relation to this group of people. As one interviewee put it, with alcohol particularly:

It can be messier I think for medics and for clinicians, they don't quite know what's going to... it's like a house of cards almost and it's when one organ fails like the liver, then what are the consequent other conditions that occur. [Substance use professional - interviewee]

Many professionals in this study commented on how service users with substance use problems might often reach the point of critical illness and then recover (often sufficiently to continue their consumption of substances) only to fall ill again. Comparisons were often

drawn between this uncertain trajectory and the more predictable journey for those with terminal diagnoses such as cancer and this was perceived as a barrier to accessing end of life pathways.

10.2.2 Failure to recognise or failure to refer to substance use or end of life services

One important observation concerned the fact that often people were referred to substance use services, if they were referred at all, at a point when they were seriously unwell. This was discussed above, in relation to working with individuals, but it is also a relevant consideration at the service level. It raises significant questions about case management, recognition of issues and possibly the level of awareness of substance use services, particularly among general practitioners and medical staff:

You have to question why you've got to a stage where someone's basically dying of organ failure and yet they've never, ever been referred for specialist [substance use] support and you have to think, I don't know, have the questions ever been raised around, "Are you drinking?" Other health issues that are going on, you know, "The damage you might be doing yourself," or is it that maybe the doctor or the people have thought, "Well, we've given a little bit of advice, it's up to them whether they think they should be taking it," or is it around maybe they're not aware of services as well that they can refer to for support as well.
[Substance use professional - interviewee]

This quote reveals a significant gap in multi-agency responses for this group of people, particularly in relation to those who are drinking at dangerous levels; a gap borne perhaps of clinicians' lack of familiarity with what substance use services can offer and issues of discomfort in relation to addressing possible addiction problems.

Hospice professionals too, while they worked with some people who had substance use issues, were aware that there were many other individuals, without problematic substance use, who were not referred for their services. While this might be due to uncertainty about prognosis, some hospice professionals felt it was also the case that many individuals might not wish to engage with a hospice service. Even so, participants felt there were still ways in which palliative care expertise could support care management in these cases.

That said, one conversation in a hospice focus group suggested that recognition by the hospice movement of alcohol and other drugs as an issue to respond to was years behind, stating that dementia was only just being recognised:

R: We don't see people who have drug problems or alcohol problems and we know that there's loads.

R: I think it's a long way off because we're only just getting this dementia thing at the minute. Dementia's been about and that's only just being, we should look after them the same as everybody else ... so I think the alcohol and drug abuse thing might be ... another 20, 30 years. [Hospice professional - focus group]

10.2.3 Thresholds, referral criteria and capacity

Inextricably linked with the theme of failure to refer are the issues of service thresholds, referral criteria and service capacity. Hospice professionals emphasised the pressures their services were under and the difficulty in meeting demand, which was made worse when they were asked to accept people who did not need hospice care to relieve pressures elsewhere.

Substance use professionals too recognised that palliative care services did not have the capacity to take on the population of people with life-shortening illness and substance use problems. Indeed, they further observed that the people they were concerned about often did not 'fit' the referral criteria for palliative care services – sometimes not even Macmillan nurses. Substance use professionals also perceived that hospitals may avoid referring people with problematic substance use to hospices as a result of stereotyping:

... we had a client who we could see was dying and he was going in and out of hospital, he was bouncing in and out with ascites problems and we asked "Can't this person be returned to palliative care?" and I asked the GP and the GP said, "I can't refer to palliative care unless the consultant did", so I said "let's ask the consultant again", so I emailed the consultant, the consultant then told me, "This person is not palliative, this person needs to stop drinking" and he died three weeks later. [Substance use professional - focus group]

10.2.4 Partnership links

In terms of partnership or joint working, hospices tended to work more closely with GP practices in the sense that they were involved in Gold Standard Framework (GSF)² meetings:

Yeah, I mean we tend to have good relationships with most of the GPs, with the GP practices. We attend the GSF meetings, which is the Gold Standard Framework meetings. That varies, some practices have them monthly, some have them three monthly, and usually at that meeting is district nurses, GPs, ourselves and if there is any specific patients with issues, such as drug and alcohol ... well, we talk about all the palliative patients but that would be a good forum to talk about, perhaps, other issues that are impacting on things. Yeah, so that tends to provide good relationships. Yeah, the GP is really good at referring to us when they need help with the cases. [Hospice professional - interviewee]

In contrast, while substance use services also reported working closely with their local GP practices, for better or worse (see Part 4 below), one of the substance use specialists specifically commented that:

² Gold Standard Framework: <http://www.goldstandardsframework.org.uk/>

I don't think our staff have ever been trained in end of life care and we certainly haven't ever been offered an opportunity or found an opportunity to get on to the GSF programme for instance. That's a gap and I suspect that's a gap right across substance misuse services.
[Substance use professional - interviewee]

The implication here being that some people using substance use services are using those services at a point where they may well die, whether this is as a result of their substance use or not, and that services need to be in a position to respond.

Links between substance use and hospice services were discussed. There was recognition that more of this was needed with some professionals on both sides not knowing who to contact or which services were available locally. However, there were some examples of effective partnership working:

We've had some very good conversations with [substance use services] about mutual patients but there's never been an opportunity for us to spend any time, on either side actually, because I think there's still quite a lot we can learn from them, there's a mutuality about it but the opportunity hasn't arisen. [Hospice professional - interviewee]

Evidence from this study also indicates that better links are needed between substance use services and medical services (hospitals and general practice). There were many reports of individual practitioners fostering links on a case by case basis but there was also evidence of a lack of routine links. Where new projects had been put in place, for example an alcohol team based in the hospital or substance use specialist based in a GP surgery, professionals reported significant benefits. There is also evidence that medical staff, including specialist consultants, are not recognising end of life needs for this group, and are not therefore referring to end of life services. One suggestion from substance use professionals was to try to get palliative care teams in hospitals more involved in care to improve quality of life. One of the hospice interviewees also suggested that better links between gastroenterology and end of life care would be beneficial.

Difficulties in accessing both mental health services and the social care sector, both of which were deemed essential in providing a holistic multi-disciplinary response, were discussed in some detail in section 6.2.2. Nevertheless, it is worth repeating here that both hospice and substance use professionals recognised problems in working with these agencies and ways need to be found to forge effective partnership working to provide more than a crisis response to people with both substance use and end of life needs. These difficulties were again around the thresholds, referral criteria and capacity as well as lack of appropriate provision more broadly, for example it was noted that care homes are not generally equipped to work effectively with people who have substance use problems. What was recognised too was that resources were needed to make partnership working effective.

10.3 Summary

This chapter explored policy, resources and ‘multi-disciplinary service response and pathways’ for this service user group as ‘system level’ challenges identified by professionals. Policy was seen to be impacting on service delivery for this group of people in three ways. First, the focus on the recovery agenda for substance use services was seen to be problematic where people were at the end of life but still had need of substance use expertise. Further, it was noted that substance use services are not currently included in gold standard framework planning despite the apparent increase in substance use related illness, and finally, the procedures involved when a person died in service a ‘serious untoward incident’, even if death was expected for that person, were also difficult for substance use professionals. Lack of resources and the impact of funding cuts on service delivery and commissioning pattern GSFs were highlighted by substance use professionals.

Examination of the data related to multi-disciplinary responses revealed issues associated with the unpredictability or uncertainty about diagnosing end of life for people whose health problems are related to substance use, thus reducing the likelihood of referral into end of life pathways. Another observation was that there is often a failure, on the part of GPs and hospitals, to recognise serious illness and/or refer in a timely way to either substance use or end of life services, meaning that individuals are often seriously ill by the time referrals are made. Issues of thresholds and rigid referral criteria were an oft-cited barrier to engaging other agencies in delivering care to this group of people. Consideration of the evidence on partnership links between agencies suggested that there is appetite on the part of both substance use and hospice services to work more closely together. Better links are also needed between primary and acute health care and substance use services and both substance use and hospice services would like to see better joint working with both the mental health and social care sectors.

PART FOUR:
LEARNING FOR THE FUTURE:
Good practice, training and supporting staff

Chapter 11. Good practice

One of the key aims of this project was to highlight good practice where it existed in supporting people living with problematic substance use and end of life care needs. During the focus groups and individual interviews, there were areas of good practice identified in the participants' data³.

The following section combines data drawn from the individual interviews and focus groups. These data were independently coded with 80 coded extracts assigned to the focus group data and 32 to the interview data. The coded extracts were combined in one data set and further categorised into two themes which represent the two different sectors.

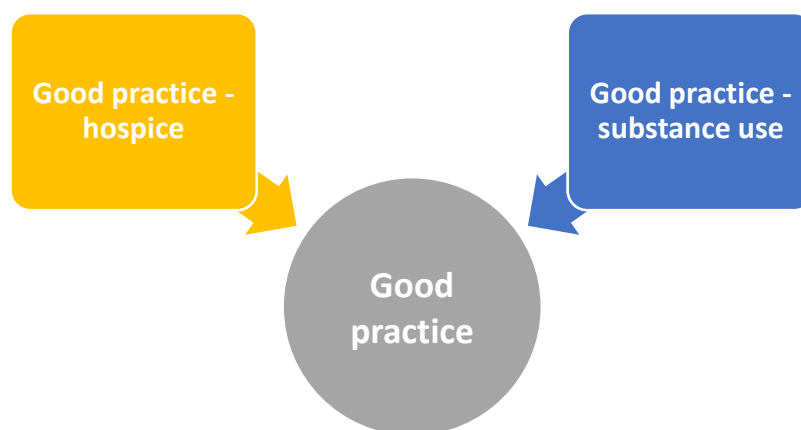


Figure11.1: Key categories relating to good practice

These themes will be presented below. They have been categorised into those relating to the hospice practice, those relating to the substance use practice, and those relating to other professionals' practice, that is, GPs and hospital care.

11.1 Good practice - Hospice

There were three clear areas of good practice identified in relation to hospice practice with people using substances; attitudinal, practical and joint working.

11.1.1 Attitudes

As the survey results showed (see chapter 3), there was little evidence of poor attitudes among these groups of professionals, just suggestions that they would like more knowledge to support their practice. However, within the qualitative data, there were two examples of attitudinal good practice; first, a commitment to non-judgemental practice with people who used substances and second, to providing a person-centred and needs-led approach to end of life care.

³ The concepts of good and bad practice are subjectively determined. The practice identified as good or bad has been labelled as such by the report authors. It is possible that others would interpret the practice differently.

I don't think being judgemental and trying to adjust or stop behaviour that's been going on for decades, in some cases, for somebody who's imminently dying, is appropriate, but it certainly does affect how you manage their symptoms [Hospice professional - focus group]

Much of this lack of judgement appeared to stem from building and maintaining relationships with people and a professional focus on addressing individuals' needs:

I think it's building up a really good relationship so that they're honest with you and give them permission to be honest in terms of what they've taken, what they're taking now, and explain that we're not going to be judgemental over that, we just want to establish it so that we can help them. [Hospice professional - interviewee]

The doctors, in particular, they will make sure that for instance, if somebody is coming in and they have an alcohol problem, ... they make sure that ...it's the person, it's not the alcohol, it's the person that's most important. What they do is they, they administer the medication around the person, not alcohol central, around the person
[Hospice professional - interviewee]

The limited life a person had left clearly had an impact on how professionals responded to people's substance use with professionals reticent about stopping people from having what they liked in the final period of their lives:

... they've been using those substances is as a coping mechanism and they're facing probably one of the most difficult times in their life, and what we don't want to do is say, "Well, you can't have that". And try and control it as best we can to keep them as well as possible, but still deal with the issues that they've got going on. [Hospice professional - interviewee]

There were also examples of innovative and non-judgemental practice from individual professionals, some of which went against their professional education and training. This included offering nicotine patches to people at the end of their lives who could no longer hold a cigarette, and the following example:

I saw a patient in a nursing home who had dementia caused by alcohol and he was very agitated and I was sat talking to him and he kept saying to me, "Jack Daniels, Jack Daniels" and I said, "Why don't we just get this gentleman a Jack Daniels rather than go to the cupboard and get him a shot of [medication] to calm him down?". So, he got a mix of Jack Daniels and lemonade and he calmed down. ... Again, it's about he's abused alcohol so now why are we stopping him when [he's] in the last few days of his life, actually just having a sip and a taste of it and nobody had addressed that....This sort of thought process and advice goes against everything, when you go and do your nurse training, ... if you wrote that in your nursing exam, you'd fail wouldn't you?! Talking about how to

address psychological needs and things, “give them some alcohol”, you'd fail wouldn't you? [Hospice professional - focus group]

In general, the qualitative data demonstrated positive attitudes in the hospice sector towards people with substance problems even when this challenged their traditional health promotion roles and professional training.

11.1.2 Practical solutions

The hospice professionals also offered practical solutions for people with problematic substance use including a fridge for alcohol for people who were in-patients:

...we have a fridge that people can put alcohol in, we've had a few patients recently who were alcohol dependent and it's been open and they've had alcohol and it's accepted that that's what they need and we work with them [Hospice professional - focus group]

They also offered safes or safe spaces for people's homes to protect the drugs from friends or relatives with substance problems who may be diverting the drugs for their own, or others', use:

There's a set of four core drugs that are issued to people at the end of life that are kept in the patient's home and used for symptom control ... but in some cases we've had to have these drugs locked away somewhere safe in the house. [Hospice professional - focus group]

I had a patient whose son was a heroin addict and he kept all his medication in a rucksack which he kind of kept under his pillow almost, and we ended up putting his end of life medications and stuff in a safe under his bed. [Hospice professional - focus group]

Family members or friends who used substances was the key concern about safety of the drugs given the possibility that they would take and use them. While some practical solutions were available within the service, it was clear that others relied on the initiative of the individual professionals.

There were also examples of good practice in relation to joint or collaborative working. The examples were few, however, and appeared to rely on the interest or good practice of individual professionals externally.

11.2 Good practice - substance use

The good practice for the substance use services fell into similar themes as the hospice staff; attitudes and joint working. A third theme identified the model of practice or practice approach as one that offered features that other services did not.

11.2.1 Attitudes and reflective practice

People deserving the best treatment no matter what their health or substance-related problems are, was a feature of discussion with substance use professionals as well as the hospice professionals:

R 1: No matter what your illness is, you deserve the best possible treatment and that has been, I hate to say [it], alcoholics are being failed on a grand scale ...

R2: It's not just you deserve the best treatment, you deserve the best death that is possible for you.

R1: Absolutely, if that's the route you're going. You still deserve the respect. [Substance use professional - focus group]

The substance use professionals also reflected on the wider context of people's lives and the overwhelming difficulties that led to their substance-related ill health:

...it seems completely alien to us why somebody would drink themselves to death but when you understand the context of somebody's life and the things they've been through, it makes sense and I suppose that that's the really, very, very sad thing, you really do understand the struggles people have had and this is not about a choice to just drink myself to death, it's being overwhelmed. [Substance use professional - focus group]

One person pointed out how substance use professionals were used to "dealing with uncertainty" and reflected how their skills in doing so are transferable to talking about death and dying:

... when we're talking about maybe somebody isn't going to live too much longer, we can sort of have those discussions about, "All being well, if things continue, we've got this lined up and, worst case scenario, if things aren't going so good, we've got another thing lined up." I think we've got some transferable skills in dealing with uncertainty, if we can just take a leap and move those skills in talking about whether you're drinking or not drinking, to whether you're dying or not dying, sorry that sounds really blunt, but you know what I mean. [Substance use professional - focus group]

This identified 'transferability of skills' is one which further training and education can capitalise on and training is discussed further in chapter 12.

11.2.2 Positive approaches or models of working

One of the substance use services had a project specialising in supporting people whose alcohol consumption had resulted in liver problems, another specialised in supporting older people. The development of these projects had included a more holistic approach to practice that allowed staff and volunteers to spend more time with people, and to provide information in a range of formats including pictorial and written information on their liver problems:

... the project had different terms of reference to a lot of the other projects, I was spending probably four hours a week with three or four clients and you do get to know them much quicker and much better and you did actually get a reasoning of what their thought process is.
[Substance use professional - focus group]

...we have a full remit to do whatever sort of things that we needed to do to support clients, which was going to the doctors with them, going to PIPs assessments with them, taking them to surgery, helping them get their medication and really using the hospice model of volunteer kind of support, rather than the classic very risk averse addiction services... .
[Substance use professional - focus group]

I've got some clients that it's quite easy to sit down and go, "You know it's your liver and you know this and you know that." And you're just talking to them and they haven't got a clue really, they're going: "Oh yes, oh yes." So I've got pictures and paperwork that I give them to keep and have a read in their own time... . [Substance use professional - focus group]

Other groups spoke about their persistence in trying to engage people who had lost touch with their services including outreach where possible into people's homes:

We do go to lengths to try and engage with clients because I've heard of some services where you'll get a referral, you'll try and contact once. If that person then doesn't either engage or respond, it's almost like, "Well, we've got too many other people wanting treatment and support, we can't spend time on chasing people all the time." So they'll then either discharge or not do anything with that person and then just move on. Whereas, ... we'll always try and do that little bit of extra chasing just to look at, "Is the service right for you? Do you still want our support or is there anywhere else we can maybe refer you on to if you thought this wasn't the right service as well?" [Substance use professional - interviewee]

... they'd be sent a letter with an appointment and perhaps they'd have a phone call and try and do it that way. If we don't hear anything, if it's been so long then they'll get a letter saying, if we don't hear within seven days it will be closed down. Whereas I'd ring the GP, I'd see if they're booked in to see them, can I come along to that appointment or I'll ring the social worker or environmental health worker, I get in touch with them, have you seen this person, can we arrange a home visit. I do quite a bit of outreach work, try and do it that way.
[Substance use professional - focus group]

Advocacy was also an important part of their work with this particular group of people:

Being flexible about home visits, being an advocate, taking on the advocacy role. Normally we'd want an empowerment role when people come to us in a generic alcohol service, but I think actually, we've experienced that people just haven't got the energy, they haven't got the physical energy to fight battles all the time and we need to take on their case. ... So, I think it's the willingness to go there and do some of that that's possibly more of an advocate than an enabler, maybe.
[Substance use professional - interviewee]

Another group spoke of their approach being to keep people 'stable' rather than setting or pushing for goals as they might normally seek to do:

R: I suppose when they've built up all the risks and all the problems, it then becomes a case of trying to keep them stable. So, you stop doing the working through treatment and ...
R: You're just managing it aren't you.
R: So, I mean I have a lady that has got COPD that keeps getting infections. ...She's regularly in and out of hospital. It seems as if the medical side of it as well is just a question of trying to keep everything stable, to keep her going. [Substance use professional - focus group]

Finally, one agency had located their staff within a hospital setting and had found that had improved the links and service they offered:

I think the alcohol liaison team that we have in the [acute trust] at the moment, ... is the best provision we've ever had for our clients. It never existed previously, it didn't exist, so there is links there and there is an active team that works within that Hospital Trust to identify those clients that are in danger through their alcohol use.
[Substance use professional - focus group]

Thus, key characteristics of the models or approaches that supported people well were: time to build relationships fully; being proactive in trying to engage people in services; being able to recognise that 'normal' rules of practice and engagement might not apply with this group of people; and having a service located within an organisation with whom you can develop positive links.

11.2.3 Joint working

While highlighting the positive elements of practice and joint working, it was clear that a great deal of collaborations did not work or could not be established. Some professionals offered solutions to these more negative working practices including one professional who stated that the ideal future substance use service would have a link with the palliative care team and learning about their multi-disciplinary team approach.

As previously mentioned, two groups of people came in for particular criticism from the professionals involved in this research – GPs and hospital staff. Some participants suggested the partnership challenges could be overcome. In particular, working to develop professional relationships with individual GPs and consultants, and doing this through

meetings was emphasised by some. Others suggested accompanying people to their appointments with GPs or with hospitals in order to offer support and advocacy.

As a rule, we try and have a conversation with a GP or we go to the GP appointment with clients and encourage them and model assertiveness and say, “If you can’t talk about that now, can we have another appointment to talk about mental health issue” or whatever, so actually getting involved with GPs and going along with people is kind of like the way in. [Substance use professional - interviewee]

... when I have got through and had conversations with GPs or my colleague has accompanied people to a GP appointment, we’ve had some fantastic interactions, really worthwhile partnership working that you come out with a proper plan and you feel buoyed up again and more direction, so when it works, it works excellently, it’s just getting the time to make it work. [Substance use professional - interviewee]

There were also examples of hospices “looking outwards” [Substance use professional - interviewee] to develop partnerships, particularly to address capacity issues.

11.3 Section summary

This chapter has highlighted three particular areas of good practice in relation to hospice staff. The first concerned their commitment towards a non-judgemental attitude in working with their service users along with a strong focus on providing a person-centred and needs-led approach to care, including working with a person’s choice to continue using substances (in a safe way) at the end of life. Hospice staff had also developed practical solutions to the tensions inherent when continued substance use and end of life needs overlap, such as safe places for storage of drugs within the home. They also showed a commitment to working collaboratively with other agencies and services wherever other agencies were able, or prepared, to engage.

Positive attitudes and reflective practice were also highlighted in relation to the practice of substance use professionals – who again were empathetic and emphasised that people deserved the best treatment no matter what their circumstances. Discussion of some of the specialist projects run by the substance use professionals in this study highlighted particular models of working which were felt to be helpful for people with complex needs. These ways of working allowed for more time to be spent with people, supporting and advocating in a variety of contexts and also ensuring that information was provided in a format which was understandable. Persistence in trying to engage service users was also noted.

Chapter 12. Training and support needs

This chapter presents data on the training experience and support needs of both groups of professionals – hospice and substance use services. It begins with data from the survey which explored training experience, perceptions of training importance and need, and incorporates qualitative data from the interviews and focus groups. It also highlights the support needs identified by professionals in the course of the data collection and which are important in supporting staff to continue working with people with problematic substance use at the end of their lives.

12.1 Training needs

In order to respond to the challenges staff identified, and to ensure this research supported practice development, the professionals were asked about their training needs. In the survey they were asked about the importance of training and given a pre-set list of topics and asked to rate how important they were to their practice. In the focus groups and individual interviews, a wider discussion was held about training already provided and training needed.

The survey responses suggested that, on average (median), substance use staff rated the importance of training in palliative and end of life care higher (8/10) than the hospice staff did in relation to substance use training (7/10). However, hospice staff identified 10 topics in which more than 50% of the respondents (n=34-38⁴) felt that training was important, including the impact of substance use on physical and mental health, how to talk about substance use, and the types of treatment available. The largest response was a call for training relating to pain management (see figure 12.1 below).

In contrast, more than 50% (n=15-18) of the staff from substance use services indicated training was very important in all but one area of possible training, which was 'prescribed drug use for life limiting conditions' (see figure 12.2 below). In the remaining 12 areas, between 55-77% (n=20-28) of staff rated those topics as very important, with the most important being 'working with specialist services' and 'emotional responses to end of life care'. However, 'how to talk about end of life' and 'assess risk relating to end of life' were also key topics identified as being important training areas.

⁴ Not all respondents answered all questions.

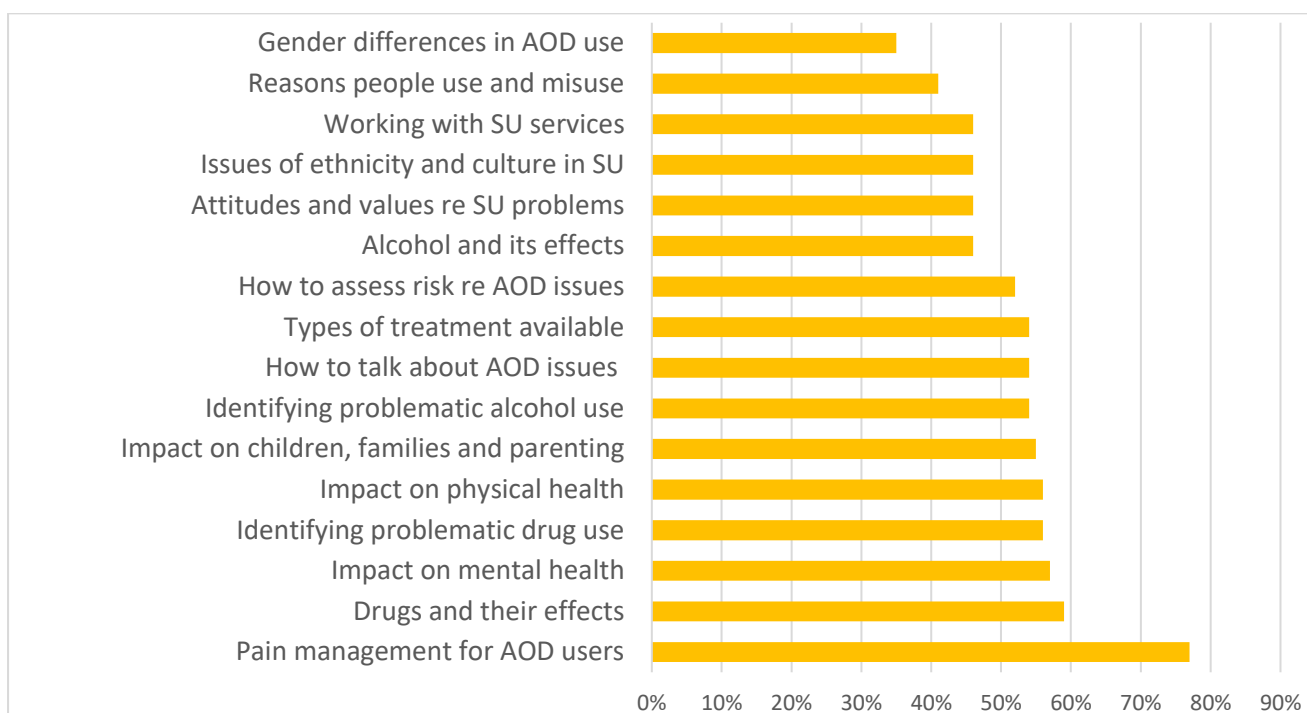


Figure 12.1: Training needs: Hospice services: % indicating training as very important (n=62-645)

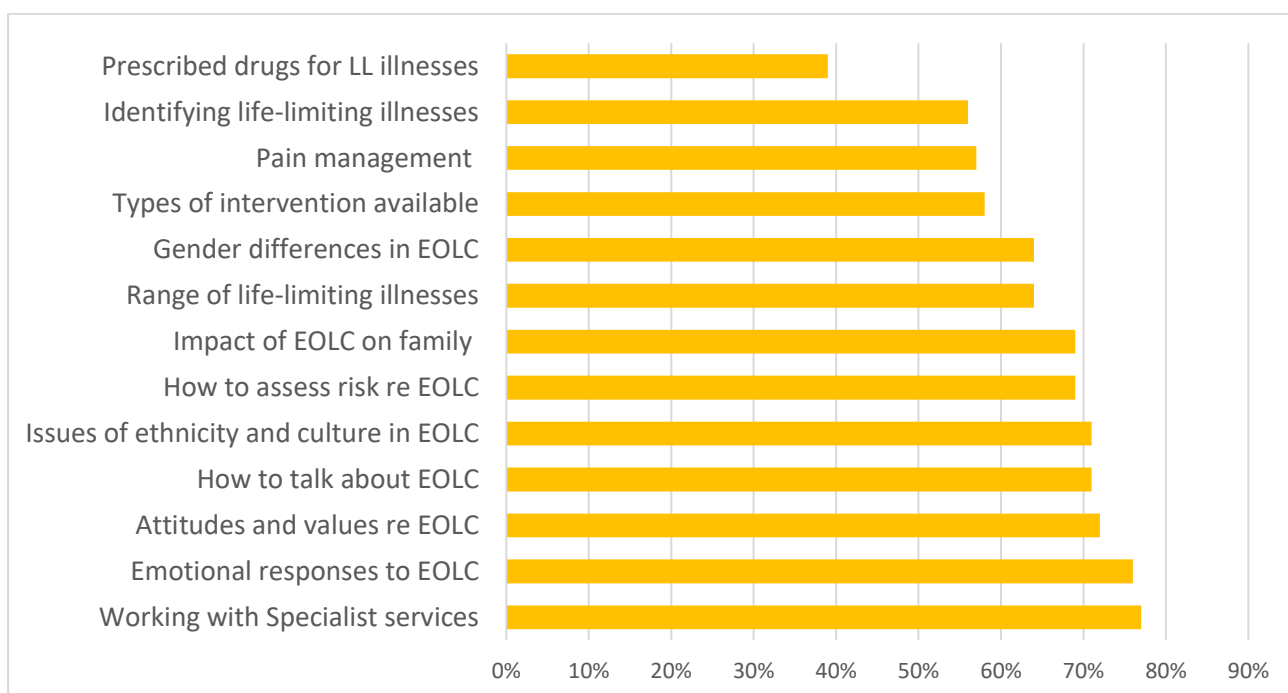


Figure 12.2 - Training needs: Substance Use services: % indicating training very important in this area (n=31-36⁶)

⁵ Not all respondents answered all questions.

⁶ Not all respondents answered all questions.

The interviews and focus group discussions led to further debate about training needs. Among the substance use staff, some reported limited to no contact of working with end of life or palliative care services and not knowing who to contact and what services were available. Some substance use staff reflected on their lack of preparation as a team for working with these issues in spite of their familiarity with health issues relating to substance use:

I think our care planning does cover a lot of the health and wellbeing aspects of somebody's care, but at what stage that turns into an end of life conversation is a different thing and I don't think our staff are particularly... we haven't trained people in that area of work and I don't think our [organisation] colleagues have either particularly.
[Substance use professional - interviewee]

Another noted their lack of qualifications making it inappropriate for them to 'counsel' people on those issues:

... the thing is we're not qualified medical staff are we, we're qualified to advise on drug related issues ... But cancer, how do you counsel someone through cancer with no training to do that, you just can't do that can you.
[Substance use professional - focus group]

Further, some comments showed they did not know who to contact for end of life care support and were not familiar with the services available to people should they need end of life care. Staff identified a range of physical health conditions including cancer, heart problems, chronic obstructive pulmonary disorder (COPD) and liver function as areas of training need. As previously mentioned, the fluctuating nature of some of these conditions and the challenge this poses for identifying when they indicate end of life care is required was also highlighted in discussions on training need.

Training was identified by substance use staff as being important for both paid staff and unpaid volunteers as was the need to ensure ongoing discussion of the challenges they faced to ensure that the training was kept current and applied. Only one person identified as having received training on end of life care before and that was with a previous employer. Yet, staff also acknowledged that this type of training would only be one part of a wider skills and knowledge development to be fully prepared for working with the complexity of some people's lives:

Yeah, as a worker, sometimes it feels that we haven't got all that knowledge, ... working with these people and it's like they just get shuffled around and there's a lot of signposting but when it comes to actually real work, we need more training and we need more skills and knowledge about what is there. [Substance use professional - focus group]

Another person commented that experience and peer support and learning was better than learning from a book or manual and that they couldn't possibly be trained and prepared for

every issue that arose. One substance use professional suggested having an expert in end of life care to advise the team as a possible solution:

So, like you would have, like a safeguarding lead for children, you have something, somebody that's more of an expert in end of life, that has that training, that can then be the point of contact within each agency.
[Substance use professional - focus group]

Some relevant training had already been undertaken by some members of substance use agencies. In one substance use service, how to support bereaved people had been a focus but staff also identified the need for bereavement training, in their own right. Another member of substance use staff stated that they had started doing specialist training with some local hospices about alcohol and drugs but that they had not yet reciprocated with training around end of life and palliative care and identified a number of areas to focus on:

... stuff around partly multi-agency work, but also how to manage that discussion, broaching the topic, helping people think through their decisions. Helping them plan, helping them advocate and negotiate and building clear pathways and routes into palliative care. Those would be the broad areas I think that you'd need to focus on.
[Substance use professional - interviewee]

The hospice staff in both focus groups and individual interviews provided a diverse response about the need for training. One person stated that the need for training on substance use had not been identified but highlighted how the research had prompted greater reflection, while another said it was not a priority:

... it's not been identified as a need really at the moment, but I think going forward, that might be something that you've raised, it, it might be something we need to be considering. (Hospice interviewee)

I think it's probably a greater need on other things, but I think there's still a need there. [Hospice professional - interviewee]

However, other hospice staff identified a range of training needs from "any training" around alcohol and drugs to specific needs such as "managing palliative pain" and prescribing practice for people with substance problems. Concerns about pain management and prescribing is a common theme through the wider project of which this report is part, particularly in relation to opioid prescribing for people with histories of problematic opiate use.

As with their substance use counterparts, hospice professionals wanted to know how to start conversations with people about their substance use (see chapter 7 for further discussion) and, subsequently, who to seek substance use expertise from.

- Participant 1: I think also training in opening up conversations and talking [all agree] because we've always had training in how to care for people but actually it's about talking to people and their problems and then how you can address it in palliative care.
- Participant 2: It's knowing what to do with those problems, it's like what do you do now?
- Participant 3: Ask the question, you've got to have an idea what the answer is going to be or at least have some, I always say if I don't know anything, I'll go and find a man that can, but I need to know who that man is if I don't know the answers. [Hospice professional - focus group]

It's about skilling them all up to be comfortable in, perhaps, asking those questions that perhaps are a bit more difficult to ask. So, for me, I think it's about that really, sort of, increasing awareness across the hospice. [Hospice professional - interviewee]

One hospice professional stated that they'd like to know what people with substance use problems wanted them to do so they didn't have to ask family members who might not know, or make decisions without their input because they are too ill to say:

I would say if you ever did a study with people who are either alcohol or drug dependent, what would they want? Tell us that. What do they want? Because very often they're too ill to find out what they want, and then we're doing it for them. [Hospice professional - focus group]⁷

One similarity between the hospice and substance use professionals was the reflection that staff within both specialist areas of practice were already skilled communicators and that the skills they had could be transferred to talking about the 'other' issue. Some participants considered this to be a matter of confidence or comfort in asking questions, or talking, about the unfamiliar:

I think it is about, it's as much confidence as it is skills because I think we've got a lot of wonderful people focused workers that are really good in general with people. [Substance use professional - interviewee]

Part of the reason we employ them is because they've got good interpersonal skills, but also we do give them ongoing training, so we offer an advanced communication skills course, which is for a day, so although it's talking about difficult conversations, and although most of that focus is around end of life, actually the way that you structure that conversation can be the same for any difficult conversation.

⁷ One of the strands of the wider research project of which this report is part has done just that and spoken to people at the end of their lives about their substance use needs and experiences and to people in substance use services about their end of life wishes (Ashby et al. 2018).

[Hospice professional - interviewee]

Another similarity was an acknowledgement that training was needed around what a care pathway “might look like” between the two specialist areas of practice [Substance use professional - interviewee]. Finally, there was a good example of practice from each specialist group, whereby agencies - the hospice or substance use service - had trained other health and social care professionals in the wider social and health care workforce including, in the ‘other’ specialist area of practice.

12.2 Support for staff: safety and well-being

A clear theme from the data for both groups of professionals was the additional emotional labour required when working with people with both problematic substance use and end of life care needs.

Substance use staff spoke of the emotional stress and toll from working with people who were dying. Their comments reflected their sadness that their service user should die from a substance-related illness:

...it was really sad to see them dying and I was really upset ... this is not how they want their life to be, not the script that they wrote for themselves, it’s just where they are... [Substance use professional - focus group]

While this was not the same for the hospice staff, there was, nevertheless, a number of concerns and fears over safety in relation to home visiting and prescribing in the community with a solution of visiting in pairs where there were any risks identified ahead of time.

Participants described three different aspects to the concept of support for staff:

1. Personal safety concerns during home visits;
2. Formal support and supervision from line managers;
3. The need for additional emotional support specifically related to working at end of life with people with substance use difficulties.

12.2.1 Personal safety concerns during home visits

In the focus group and individual interviews, personal safety was only mentioned by hospice staff, perhaps partly because home visits are more common among palliative community teams than among most substance use teams. Hospice staff described how they followed general personal safety approaches used in district nursing including visiting in pairs if necessary:

R3: I think we’re lucky we’ve got that facility [visiting in pairs].
R1: Yeah, but you would anyway if you were district nursing, wouldn’t you if there was a risk? You would visit in pairs if it had been identified that they were always drunk or, yeah.

[Hospice professional - focus group]

Safety concerns not only related to risk from the person, but also from their family and network of friends.

It's not just about her [hospice community service user], it's about her circle of friends, it's about her daughter. Her door is open: people can just walk in and out. You can go in there, she could be fine, but I could go in one day and actually her daughter and her mates could be there. [Hospice professional - focus group]

Often this was not so much a focus on the personal safety of the nurse, but concern for the wellbeing of the person and their family or carers from other family members (see section 9.2).

However, specific concerns were raised by one participant about being a nurse prescriber and the potential for individuals or their visitors to want to steal a prescription pad:

I won't even let them know that I'm a prescriber. I've had that where somebody knows, they're waiting for you to get the pad. So, there is a huge safety issue, but still that shouldn't prevent somebody from getting the care they need when they need it. [Hospice professional - focus group]

None of the participants in our hospice interviews had specific work policies or procedures for working with people with substance problems. In some cases, this left nurses relying on their personal perceptions about drug users to gauge risk:

A label in some respects is a good thing, God forgive me for saying it. ... But that situation that I walked into and I thought, "Oh my God where's the door?" And I'd walked straight in and he'd then gone behind me, and I thought, "How do I get out?" But he'd gone out to show me that he'd just shot up and he were like that. But I'd gone in on me own and I'd actually been advised ... I didn't realise he was at home you see, I thought his dad was on his own. [Hospice professional - focus group]

It is interesting to note that the examples of 'risk' that people described in the interviews were of perceived risk that did not turn into a challenging situation. This raises the question of whether some nurses may feel unduly concerned about working with people who use drugs. As the following focus group participant discussed, what may be perceived as concerns about 'risk' are sometimes not driven by personal safety concerns but rather anxiety over being judged to have acted unprofessionally if something goes wrong:

Because nurses as well, nurses are very different to doctors in that ... you have to be mindful of what you're doing, because if you make a mistake, you're threatened with this, this and this. Doctors don't think like that. Doctors think if we make a mistake, we learn from it. Nurses are fearful. [Hospice professional - focus group]

Although the situation may be different for hospice inpatient services (where the personal safety of staff is not combined with issues of peripatetic/lone working), one member of a hospice focus group described how she thought some hospice staff were unaware of the way that some drug users may try to ‘manipulate’ them, specifically into staying longer in the hospice, describing her colleagues as “a bit naïve”.

12.2.2 Formal support and supervision

Many participants – from both hospices and substance use services – described the value of being able to develop care provision through a team approach that supported them in their decision making:

So everybody attends the MDT [multi-disciplinary team meeting] and you would discuss difficult situations at this. We can also go the medics anytime if we want to, to ask, which we would do, and maybe if the GP didn’t have the knowledge to deal with it, we could ask our doctor at the hospice and take it back to the GP. So, I think we are quite well supported. [Hospice professional - focus group]

Because [the liver disease support group] has been going for so long as well, and like I say there’s a lot of staff members here that have been here quite a few years, it’s just normal to talk about it. Even when I have my supervision for the [liver disease support group], my manager will go through each caseload and we’d discuss in depth and then she’d ask me how I felt about it, and was I okay to carry on, if it was a bad case. [Substance use professional - interviewee]

As mentioned above, none of the hospices participating in our research had specific policies or procedures for working with people with substance problems. Conversely, neither of the substance use services had policies or guidance for working with people with life shortening conditions or palliative care needs. However, one substance use service was in the process of developing a training pack to help their paid staff and volunteers feel more confident in talking about life-shortening conditions and death with the people they worked with:

I’m just thinking of how I can put together a pack that empowers our staff to think: “This is completely transferable skills. I can talk about a situation as serious as this, I can put it in a context and I can make it work. [Substance use professional - interviewee]

Both hospices and substance use services have volunteers working for them – although in hospices they are most commonly working in reception or making refreshments. Whilst volunteers in substance use services may typically support group-work sessions or work from the service base. One of the services participating in our research had developed a service for people with alcohol-related liver disease that relied heavily on volunteers to work closely with them in their homes. This involved the provision of quite intensive support to the volunteer:

My volunteer, she works with one of my clients and we ring each other up all the time: "I'm going to see him on such and such a day, is that okay with you?" We ring each other up, update each other and it works really well. ... That's kind of like about four contacts a week isn't it?

[Substance use professional - focus group]

As substance use professionals may not consciously be aware of the emotional toll that the death of someone they had been working with can take. Managers may need to explicitly tell them to take time off, look after themselves and not automatically try to carry on supporting other clients.

The one client I lost, I got to the house on the morning and I had a feeling there was something wrong and then a neighbour came out and said, "Oh she'd passed." They'd found her passed away the day before, and I got other clients to see that day and my manager said, "No, go back to the office, that's it for the day now." So they are really, really good with that.

[Substance use professional - interviewee]

Current substance use service policies focus attention on 'deaths in service', triggering a formal 'serious untoward incident' review even if the service user's death could have been anticipated due to chronic illness. As a result, managers have to achieve a balancing act between their administrative obligations and tending to staff's emotional needs.

You don't become immune to it and I think handling sensitively the review work post-death I think is quite important - and supporting staff and individuals. People do become upset. It's hard when somebody that you've been working with (sometimes for 10-15 years in the case of some drug users in treatment) dies. [Substance use professional - interviewee]

The 'serious untoward incident' review process does not currently consider anticipated deaths and whether palliative approaches may have enabled a 'good death.' Thus, even if there is a management focus on supporting staff, the procedure does not help them or their organisation to learn from the experience and evolve good practice in relation to end of life care for people with experience.

But in focusing on the administrative procedures, sometimes the emotional toll that such bereavement takes upon staff can go unnoticed:

I'd worked with this person for a year, it was really sad to see them dying and I was really upset. But it was almost seeing that we have to get the paperwork right: [to evidence] that we did nothing wrong. And what that does is completely divorce it from having this emotional connection.

[Substance use professional - focus group]

There's a lot of emphasis [on administration], but I think I've got lost in that procedure really. It's like well how is [participant name]? This client passed away, how is she feeling? I do think that's a bit missing sometimes. [Substance use professional - interviewee]

Professionals working with a group of people experiencing substantial levels of mortality may need encouragement to recognise the need for, and time to regularly access, emotional support on an ongoing basis. This worker, involved in a specialist liver service, described how helpful they found it to have specialist emotional support outside of the organisation – partly in recognition of how working in this field could impact upon their well-being:

I'm lucky in that I've had a specialist supervisor since I've been doing the project really, so that my wellbeing is taken care of. Particularly because I've had some significant losses in the last five years, but also something external to line management, so that I can really explore the issues for me, for me and the client, the issues for the client - with somebody that's got a bit more expertise. [Substance use professional - interviewee]

However, another worker highlighted that whilst their organisation had good policies about supervision for staff, in practice this was rarely achieved. The person described feeling “on my own” as supervision was not regular. This person only had one supervision in the previous six months.

12.2.3 The need for additional emotional support

Participants from both hospices and substance use teams valued having an emotionally responsive team around them for informal, day-to-day support:

R: I think me and [support worker], we're lucky to have an office like we do because you can come back sometimes and be in such a foul mood or really upset, someone will tell you a joke or tell you stupid stories and it picks you back up then. We've also got various colleagues around the building that we can go to. [Substance use professional - focus group]

The few times I've experienced losing clients, they've [colleagues] been absolutely fantastic with me. ... If we needed time off, they're happy for us to have time off. Then they'd come and check in on us.
[Substance use professional - interviewee]

Compared to other healthcare professionals, hospice staff are likely to be prepared for, and well-supported in, dealing with death. However, as discussed earlier, they may arguably be uncertain of how to deal with or talk about their service users' substance use problems. Perhaps one important aspect of what substance use professionals learn is to work with 'ambiguity' – to support behaviour change with each service user, whilst being realistic about the challenges of achieving that change. Many substance use professionals recognise the exceptionally difficult lives that many of their people with experience lead, and often have to accept the ambivalence that some of them have towards living:

Obviously you're working at keeping that person alive, but their mental state at times can be: “I want to let go”. We can't always get in on that, that isn't easy and as much as you can talk and talk to people, nobody ever knows anybody. You never know what's going on up here, so I find

that quite difficult, it doesn't matter how close they are to you, you don't know. [Substance use professional - focus group]

But that is not to deny the emotional strain that such work places on them: It does take a toll, absolutely. One of my clients hung himself about three weeks ago I think it was. Really, really tough, it's hard when [they] pass away. [Substance use professional - interviewee]

Both of the substance use services participating in this research had at one time developed a specialist service for people with alcohol-related liver disease – one in the community and one hospital-based. In both cases, staff described how unprepared they had been for the frequency and unpredictability of mortality among this group of people.

It was unknown territory really so we didn't know what to expect. There wasn't even a job spec as such, we just thought we'd found out along the way what we needed to do. That was quite difficult, I don't think that was taken into consideration really, the problems that we would encounter. I remember being called over somewhere and you get there and the priests were there giving the last rites. It was quite bizarre really, someone contemplates that they might want help with their alcohol when they're at death's door. [Substance use professional - interviewee]

I wasn't prepared for it, as in, I thought I was helping people over 50 who had you know, drink problems, but in my head I never thought that we'd lose clients, which obviously we do. [Substance use professional - interviewee]

Aside from the regularity and unpredictability of death, there was also the impact of witnessing some distressing ways in which people's health deteriorated and also on occasion the poor quality of care that people received:

The client I was involved with, that was, in my view, a particularly nasty death he endured - and there's still stuff [a complaint against the hospital] going on with that. But that was a complete shock, he was in hospital at the time and his death came totally out of the blue. When I do think back, I still think it's incomprehensible. He was very poorly admittedly, but he was showing some signs of improvement. [Substance use professional - focus group]

In such circumstances, where deaths are not anticipated or sudden, staff may require further emotional support, particularly to ensure that they do not carry feelings of responsibility for the person's death (see chapter 5). They may also need assistance to reframe the anticipated death of a service user as an opportunity to help ensure 'a good death' - rather than considering it as having failed to support them in addressing their substance use:

For all of us, somebody dying, we're at risk of feeling a bit of a failure really and I'm not sure that we've totally yet got to the way of looking at how we can think about a good death. ... When you're in a generic service and somebody dies, you think "Oh my God." Either: "What could we have done better?" Or: "If only he'd stopped drinking." ... I don't think that there's a lot of preparation as staff that we have for these situations, let alone supporting a client who's in this predicament.
[Substance use professional - interviewee]

But even hospice staff who are used to focusing on helping people achieve a 'good death', struggled to come terms with the brief and often unpredictable timescales for people with substance problems:

The biggest thing ... I'm trying to learn [is that] things aren't always..., you can't always totally resolve [patients' problems] in the end.
[Hospice professional - focus group]

12.3 Summary

This chapter has considered professionals' self-identified level of need for training as reported in the survey and the qualitative data. It has reflected on the personal challenges and support needs of both substance use and hospice staff. Overall, hospice professionals, on average, rated the importance of training in substance use at just under 7 out of 10 (10 being very important). Training in pain management for substance users was the most important for this group of professionals. Substance use professionals, as a group, rated the importance of training in end of life care issues generally at 7.4 out of 10 and for them, training in working with specialist services was the most important. Qualitative data revealed that substance use staff saw a need for training in end of life care for both paid staff and volunteers. Hospice professionals' responses were more diverse, with some feeling this training was important and others seeing training in substance use as a lesser priority than some other areas. There were, however, three important similarities identified across the two professional groups; i) both were skilled communicators and recognised their skills were transferable to other areas of practice (given sufficient confidence in one's own knowledge about that practice area), ii) both wanted to know what a specialist care pathway might look like for people with problematic substance use and end of life care, and iii) some participants in both groups had experience of training other health and social care professionals in their specialist areas.

In relation to supporting staff in other ways, the analysis identified the need to ensure personal safety during home visits. This was particularly true for community-based hospice professionals where concerns were managed, wherever possible, by visiting in pairs. Supervision and support from line managers and opportunities for team care planning and decision making was also important as was the need for managers to balance managerial administrative responsibilities with recognition of the emotional needs of staff. A need for additional emotional support, particularly for substance use professionals working with people at the end of life, was also highlighted.

PART FIVE:
CONCLUDING THOUGHTS

13. Discussion and implications

Listening to professionals' views and experiences and reflecting that learning in policy, practice and research development is an important principle defining this research. This project was borne out of an early discussion with one of our substance use partners. They were concerned about missing opportunities to support people with serious and life limiting health problems who attended the service. Discussions with hospice colleagues mirrored this concern noting a perceived increase in people with problematic substance use presenting in their hospice. This led to a large, exploratory project with six different strands of research; this study of specialist professionals' views and experiences is just one part.

The aims of this strand of the study sought to establish the experiences of hospice and substance use service professionals when working with people with both problematic substance use and end of life care needs. It sought to determine their knowledge of the 'other' issue and their attitudes towards working with people who presented with it. Finally, it sought to document the challenges they faced in their practice with this group of people and any opportunities for innovative practice it presented. The participants were drawn from the project's agency partners: three hospices in the North West of England and two substance use agencies based in the North West and the Midlands.

Ensuring a consistent response

Initial survey data explored the professional groups' awareness or recognition of the 'other' issue. The resulting degrees of awareness between and within the teams clearly reflects the finding that people did not find it particularly easy to identify the 'other' problem. While both groups identified the main sign of the 'other' problem being physical ill-health, this is complicated by not being able to determine which part of the physical ill-health relates to the person's substance use and which to their serious health condition. These findings provide clear indications of topics for training and staff development although debates on the priority of such training reflected a mixed response once again. Similarly, the exploration of knowledge and attitudes within the survey resulted in fairly neutral findings with role adequacy, or knowledge, scoring the lowest and suggesting the need for education or training. The remaining item scores remained close to neutral score or just above.

On the surface, these mixed or neutral responses do not allow any strong implications to be drawn, however, they are likely to indicate a range of experience, a range of views, and a range of practice approaches to the 'other' issue. What this implies is a lack of consistency within and across agencies. Therefore, the response that someone with problematic substance use and life limiting illness may get in those services will vary from individual to individual. While individual variations in practice will always exist to some degree, the variation found here is not one of experience, practice style or personality alone. This variation implies a lack of clarity at an organisational level about whether and how to respond or engage with the 'other' issue. Other findings including a lack of care pathways, a lack of referral criteria, and a lack of joint working with the 'other' specialists, add to the mix of policy and practice obstacles. This organisational variation is set within a policy context that does not recognise the 'other' issue in its current policy drivers. For substance use services, its dominant policy discourse prioritises a 'recovery' agenda which, at best, is

inappropriate for this group of people and, at worst, further marginalises them from current service provision. Thus, policy development at local/organisational, regional and national level can frame practice change by reflecting the needs of this group of people in future policy guidance.

Viewing problematic substance use as a long-term condition, akin to depression or diabetes, may help to rethink the approach to care for this group of people, even at end of life. Existing guidance exists on managing multiple, long term conditions and it could be adapted for responding to this group of people (Goodwin et al. 2010).

Addressing complexity in holistic service models

A key aim of this study was to explore the challenges the professionals face in working with people with problematic substance use at the end of their lives. The findings from the qualitative data found many practice challenges at different levels. The professionals all highlighted the complexity of needs within this group of people. While most people with problematic substance use will have multiple and complex needs, the addition of life-limiting and terminal illness adds to that complexity. Someone with multiple needs including problematic substance use is unlikely to attend numerous different appointments at different places and at different times, particularly if their physical and mental capacity is limited or fluctuating. Single-focussed services are not able to provide this group of people with the care they need; a much more holistic approach is required. This was a view we heard repeatedly from the professionals in this research, many of whom were attempting to work in that way if only in short-term specialist projects. A more holistic approach allows relationships to build and trust to be established. Given the research suggests the stigmatisation by many health practitioners towards people with problematic substance use leads to distrust of health professionals and health environments, it is easy to see how this group of people may choose to disengage from services, particularly if experiencing withdrawal from, or cravings for, substances. Professionals also highlighted the sporadic attendance at treatment of this group of people. Combined, these experiences can lead to further isolation and exclusion from quality end of life care. In addition, the social isolation and loneliness that can co-exist with problematic substance use due to estrangement from family and friendship groups, can make end of life an incredibly lonely experience. However, some success had been forged with appropriately trained substance use volunteers and peer mentors. They were able to spend more time with people and offer an advocacy role as well as supporting family members and people at end of life with substance problems.

Fighting stigmatisation and ignorance

The ongoing stigmatisation by health and social care professionals was a feature of a number of strands of this research including the strand that heard directly from people at, or near, the end of their lives (Ashby et al. 2018). This strand also heard from professionals who had witnessed stigmatisation of people with histories of substance use in spite of no current use. They had also witnessed it through joint working efforts with primary and acute care colleagues. It is disappointing that such negative attitudes still exist but not unexpected given the paucity of substance use education at qualifying levels for many of the health and social care professionals including doctors, nurses and social workers. Added to this, the current climate of austerity has resulted in shrinking service budgets and increasing thresholds for service access, thus choices about who gets time and care get tougher. This group of people is likely to be one that is further marginalised in this climate of reduced

service delivery. As a result, many individuals are not referred for palliative or end of life care. Whilst this may sometimes be due to uncertainty about prognosis, or the individual not wishing to engage with palliative services, there are important ways in which palliative care expertise could support care management in such instances. Examples include: hospital in-reach (especially into A&E and gastroenterology departments) or community outreach for people who have alcohol-related organ damage. Sadly, Substance use services were seen to be used by other organisations as a bit of a ‘dumping ground’, particularly for people who fall outside the strict mental health service eligibility criteria and thresholds for support.

It is, therefore, even more important that any contact with health and social care professionals counts in terms of offering understanding, support, and engaging people in services. This needs to be backed by education and training on substance use and critical self-reflection on personal attitudes, experiences and values towards substance use and people who use, for all front-line professionals. To date, the UK has failed to do this despite alcohol and other drug use being the leading causes of death internationally (WHO, 2011) and despite a suite of guidance documents in the UK calling on front line professional education to do just that (Galvani, 2015). Fundamentally, even if people do not want to change their substance consumption, they still have the right to respectful treatment and dignity in dying.

However, there were some exceptions, including individual GPs or a local palliative care specialist, with whom substance use professionals had built professional relationships. They offered both support to staff and were also non-judgemental towards people they supported. This good practice needs to be applauded and disseminated even though its sustainability is in question given it relies on individual relationships between professionals. Given the positive impact it can have on a person’s care and end of life experience, it highlights the importance of spending time building relationships with individual professionals from other health and social care services.

Developing knowledge and confidence

Another key finding across the two professional groups was the challenge of asking, or talking about, the ‘other’ issue. The survey data revealed low percentages of professionals from each group talking or asking about the other issue “often” (see chapter 7), and the qualitative data provided some depth to this finding. Some professionals felt it was not their job, others felt it was but were not sure how to ask or what to say or had concerns about broaching the subject. Even within teams there was disagreement about asking people about their substance use or end of life care needs with some colleagues feeling strongly that the topic had to be broached as early as possible and others citing it as an irrelevance to their work. As mentioned above, the variety of approaches and views even within teams suggests there is not clear practice guidance on this topic and a possible resistance and lack of confidence for people to engage with it. Both substance use and end of life are sensitive topics and require some knowledge, tact and confidence to broach with people, even for those who are used to asking personal and sensitive questions in their own fields of specialist practice. However, it can be done, and two substance use professionals provided examples of how they would do it. Others acknowledged that the communication skill set in each professional group was there, but the knowledge and confidence was not. This is easily rectifiable and there were suggestions about training, including collaborative training with mixed groups of specialists from substance use and end of life care. This would allow

networking and relationship building at the same time as building people's knowledge and confidence.

The training survey and the responses from participants in the qualitative data collection demonstrated the need for further training in a number of areas. As identified above, a particular need was training to instil confidence in professionals to start conversations about the 'other' issue with people in their service. Other ideas included developing models of brief interventions for end of life care akin to the established brief interventions for substance use. However, the data also highlighted how, for some people, this was not an area of priority for training or intervention. This raises important questions for organisational level policy to address and for the ongoing support of staff who may be required, or should already be, offering the best service possible to people with substance use and end of life care needs.

Positive prescribing

A further challenge that could be met by training and clear guidance, primarily for hospice professionals, was in prescribing practice for people with problematic substance use. This challenge was unsurprising as the Rapid Evidence Assessment conducted for this programme of research (Witham et al., 2018) identified a body of literature on this topic. Primarily the concerns centred on under- or over-prescribing medication and the responsibility for leaving someone in pain or overdosing them respectively. While NICE (2016) has issued guidance relating to the prescribing of opiates within palliative care, there is currently no guidance about prescribing of pain medication (opiate or other) for people with current or past uses of substances at end of life. This is a debate that is already taking place and could be crystallised further into a broad guidance document supported by NICE.

The challenges of poly prescribing and keeping track of medication for people whose service attendance was erratic was a cause for concern, as was the diversion of medication by people around the individual for whom the medication was prescribed. In addition, there were safety concerns from community-focussed hospice professionals about homes where people were using and the potential danger from other people within those environments. However, again there were examples provided of how professionals had worked with a pharmacist or provided practical solutions, for example, a safe storage box, to address some of these concerns. Further, the training collaborations previously mentioned could usefully include a focus on the 'reality of risk' from people using substances.

Tailoring family support

The professionals' reports of family member involvement in a person's care illustrated how such care could fall on any point of a cross spectra of family support (see figure 13.1).

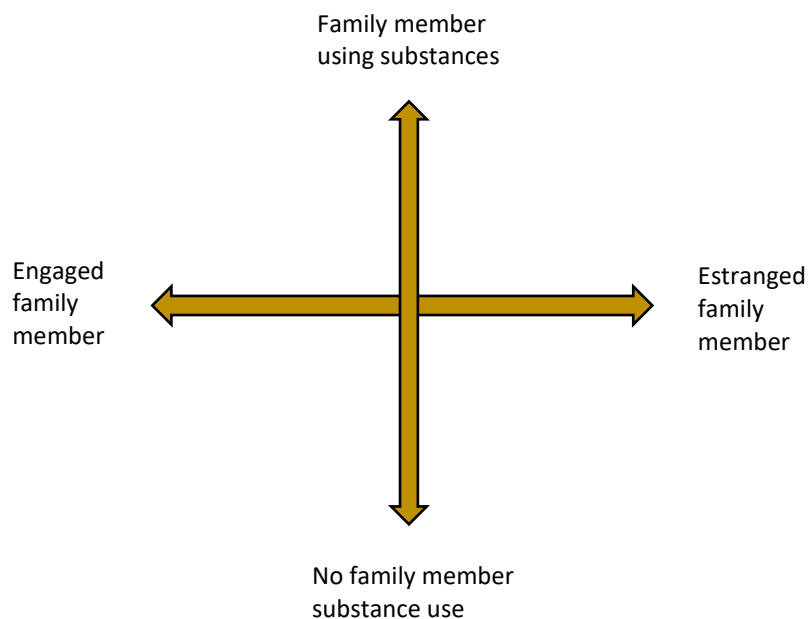


Figure 13.1. Cross spectra of family member involvement in their relative's care

At one end of the horizontal spectrum is the family member who is engaged with their care and offering appropriate support; at the other, is the family member who is estranged from their relative and not wishing to effect any reconciliation. This is crossed by a vertical spectrum which has substance using family members at one end and non-substance using family members at the other. It is clear that the professionals' experiences drew on their involvement with family members at different points along these spectra and that this brought complexity to their care of the individual and their family. Added to this mix was the emotional responses of family members and the behaviour of family members whose expectations about their care were not being met. Similarly, professionals struggled with the behaviour of those family members who were intoxicated or who abused or diverted medication kept in the home of the ailing relative.

These experiences are a far cry from a perception of family members as only being supportive and caring at their relative's end of life. However, the lack of arrangements for family support in the hospices, in particular, demonstrates the need for a service to fill this gap and potentially ease some of the pressures on the professionals.

Research exploring the needs of family members of people with problematic substance use has shown how support for family members in their own right can improve their health and well-being (Orford et al., 2010). Similarly, research into the experiences of family members bereaved through a relative's substance use has also shown the stigma, shame and emotional strain placed on surviving family members (Templeton et al., 2016; Valentine 2017).

The complexity of the support and communication required with family members, further suggests that professional support for family members may need to be tailored according to individual need and that support options need to be available both within the service and in active partnership with other services. This would require some form of assessment process and recommendation of a package of care to fit their needs. This could include written information on how best to support a relative at the end of life, including behaviour and communication suggestions.

The professionals' experiences also suggest that working with family members will require some education, training and resources for the existing staff set within a clear organisational policy framework.

Developing policy to support practice

Section 13.1 has highlighted the inappropriateness of the recovery discourse in national policy frameworks for supporting this group of people. At a front-line level this recovery focussed target appears to leave professionals feeling responsible for people who die while engaged with substance use treatment. Previous policy discourse around harm reduction may be more helpful with this group of people than the recovery focussed agenda that states: "We are clear that no-one should be left behind on the road to recovery" (H.M. Government, 2017: 28). As professionals in substance use services pointed out, there is no measure of success for someone dying with dignity or in a better place than they were prior to their involvement. Thus, national targets and indicators of success clearly need rethinking for this group of people and the professionals who support them. While such changes are awaited, at a local and organisational level, there could be independent indicators of care and support introduced for this group of people – indicators that reflect the support and care offered to people prior to their deaths plus any advance care planning or end of life orientated discussions.

Further, it is clear from our findings that people at the end of their lives with problematic substance use, and the professionals who support them, require a policy framework that supports better partnership working and improved pathways to care.

Promoting good practice

While GPs and acute care professionals came under a great deal of criticism regarding their attitudes towards people with problematic substance use and health problems, the professionals from both substance use services and the hospices showed overwhelmingly positive attitudes towards this group of people. The apparent lack of judgement shown, combined with the individual examples of innovative practice, practical solutions, advocacy, and 'going above and beyond' to support people, showed a real commitment from staff. Some of the hospice staff highlighted how they responded very differently to people with problematic substance use because they were at the end of their lives; they sought not to regurgitate their health promotion role at this point and to take risks they might not otherwise take. This did not always sit comfortably with them.

However, what was also transparent was that time was needed to build relationships with individuals and how a more holistic approach, described by some substance use professionals allowed for this and resulted in closer working relationships and a better understanding of people's needs.

Achieving good practice will require better knowledge and understanding of the 'other' issue, as outlined above. This knowledge transfer could be addressed in training programmes or staff exchanges which would also encourage more partnership working.

Supporting professionals

While training needs have been identified throughout this report alongside the need for policy frameworks that support practice and practitioners, the final area of support need to be addressed is the emotional strain on professionals of working with this group of people. Death rates are higher among substance users than in the general population and, staff are likely to feel the losses more keenly particularly when working more intensively or holistically with people. Recognition of the need for bereavement support for professionals would be helpful in supporting their resilience and positively affecting staff retention.

Stereotypes concerning the behaviour and presentation of problematic substance users were apparent among some hospice staff and such expectations can unduly unnerve care staff. Improving their knowledge and understanding of substance use, and their confidence to deal with it should help.

In the current climate, there are additional pressures on professional staff to do more with less resource. Identifying transferable skills from their current practice and applying these to the 'other' issue is a way forward as well as identifying an allocated expert locally from each sector to actively engage with and advise the other services.

13.1 Limitations

This study involved professionals from the substance use and end of life care agencies who were agency partners for this exploratory research. Its findings are limited to their experiences of practice and are not generalisable beyond the boundaries of this study. There are, however, commonalities in the findings within and across the two groups. This suggests some findings are highly likely to be found in the wider substance use and end of life care sectors, for example, challenges in talking or asking about the 'other', and their shared experience of negative attitudes from primary and acute care professionals towards people with problematic substance use. Within the sample of substance use professionals were people who had worked on specialist older people and liver projects and their practice and understanding is possibly more developed than substance use professionals not working with those groups routinely. The survey sample for the study produced fewer respondents than hoped and the median scores of each professional group on the knowledge and attitudes questionnaires were very similar and group sizes were relatively small, therefore, comparative statistical analyses within or between groups was not undertaken. Further, the study was exploratory and focused on describing experience rather than testing hypotheses; we also utilised a tool adapted specifically for this study and statistical comparisons would not be appropriate. Finally, the study's participants, with the exception of one Midlands-based agency, came from the North West region of England. It is possible that a wider group of agencies with geographical spread might produce different findings. The North West region, however, remains one of the areas with the highest rates of harm relating to alcohol and other drug use.

13.2 Implications for practice

The learning from this study suggests that, for improvements to be made, practice managers need to:

- Develop effective partnership working protocols between substance use and end of life care agencies to support both sets of staff in responding to challenges as they arise.
- Work towards better partnership working with other social and health care agencies, such as mental health and adults' social care, incorporating care pathway development.
- Offer local training and practice guidance at an individual staff and organisational level about working with these overlapping issues. This would include how to talk to people about the 'other' issue. Developing and integrating training with the 'other' specialists would be ideal.
- Develop practice guidance on pain and symptom management for people with current or previous use of substances at end of life.
- Develop guidance on working with families of people with substance problems including assessment and support of family members in their own right.
- Remind staff of their transferable skills base for working with sensitive subjects and ensure they have sufficient knowledge of the 'other issue' to underpin their practice.
- Target local primary and acute health services to build relationships and offer information, training and support.
- Ensure support and supervision for staff identifies and addresses the emotional impact of work in this area.

13.3 Implications for policy

Developing policy at different levels will support professionals and agencies working with people with using substances at the end of their lives. Further policy work should include:

- Developing organisational level policy on working with people with overlapping end of life care needs and substance use. This should include policy decisions on access to services for this group of people, routine questioning, recording and monitoring, appropriate responses, joint working and referral practice, to name a few. It should be accompanied by practice guidance and training as appropriate.
- Developing organisational policy around working with family members of people with substance problems at end of life and consider what support can be offered in house and what support is more appropriate for referrals to other specialists.
- Reviewing existing models of care at an organisational level to maximise opportunities for holistic approaches to care, incorporating volunteers and peer mentors.
- Developing local and regional level policy bringing together substance use and end of life care agencies and relevant front-line partners to work towards a policy framework which is responsive to local needs and considers current funding and service pressures in seeking ways forward.
- Highlighting to national policy makers the inappropriateness of substance use 'recovery' targets for this group of people and to work with them to develop more appropriate targets which also support staff efforts prior to a person's death.
- Working regionally and nationally to change the stigma and stereotyping around substance use, e.g. through regionally and nationally funded campaigns and regional public health involvement.

- Contributing to national level policy debates around end of life care and substance use, particularly with a focus on health inequalities and access to services.
- Reviewing current national policies in both areas of specialist practice to consider how to include the 'other' area; for example, the inclusion of substance use services in the Gold Standards Framework for End of Life Care, or the inclusion of end of life and palliative care within alcohol and other drug strategies.

13.4 Implications for future research and knowledge exchange

This was an exploratory study with a purposive sample of hospice and substance use agencies. Future research needs to:

- Develop, roll out and evaluate a gold standard model of care for working with people with problematic substance use and life limiting conditions, including clear care pathways. This will help to improve access to end of life care for people with problematic substance use.
- Research the experiences and perspectives of a wider group of health and social care staff towards people with problematic substance use and life limiting conditions. Given the findings of this research, this should focus on primary and acute care staff and social care professionals.
- Scale up the research conducted here to include national populations of staff working in both substance use and hospice services. This was a purposive sample only and a larger sample would determine whether this was an accurate picture of the experiences of end of life care and substance use services.
- Collation and dissemination of existing good practice as identified in the existing evidence base and this research.

Conclusion

This research set out to explore the experiences of health and social care professionals working with people with problematic substance use and who were nearing the end of their lives. It sought the experiences of two groups of professionals; those working in three hospices, and those working in two substance use services. Included in these practice and clinical experiences were those working with the family, friends and carers of people in their care. This research also sought to assess the attitudes and knowledge of these professional groups towards working with the 'other' issue, that is end of life care for substance specialists, and substance use for hospice specialists. Finally, it sought to establish what the challenges were these groups faced in supporting people, and their families, where there was co-existing substance use and life-limiting illness.

While attitudes towards people with these co-existing issues were generally positive to neutral, it was clear that the professionals lacked enough knowledge to provide them with confidence for working with the 'other' issue. The complexity of combined substance use and a serious health condition added to the challenges of identifying and responding to people given the fluctuating nature of both issues making it difficult to determine what belonged to the substance's effects (or withdrawal from) and what was related to their ill health. Professionals reported difficulties asking about the 'other' issue and no routine assessment thus making the identification process more difficult. They were, however, aware of the stigmatising and stereotyping of people with substance problems from other professionals and the impact this could have on referrals to services and care provision.

A number of key challenges including medication and pain management, supporting family, friends and carers, and working within an emotionally challenging context were noted. At a systems level, funding cuts, limited resources and the lack of partnership working stifled innovation and practice. Training needs were identified including how to talk to people about the 'other' issue, an essential requirement for accurate needs assessment. However, there was some good practice cited including supportive team working, and good individual relationships with key community and hospital-based practitioners.

The lack of consistency in practice, however, suggests the need for a policy framework that can drive greater consistency across services. It also needs to ensure professionals are supported by training and practice guidance to offer the best care to all. This group of people appears to face a number of inequalities in relation to end of life care, including access to hospice care. It is time to offer this group of people dignity in dying through services that are able to deliver a package of care most suited to their needs and based on a holistic assessment process.

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